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Disability Rights and Independent Living Movement Oral History Series

Corbett O'Toole

ADVOCATE FOR DISABLED WOMEN'S RIGHTS AND HEALTH ISSUES

An Interview Conducted by
Denise Sherer Jacobson
in 1998

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Corbett O'Toole, "Advocate for Disabled Women's Rights and Health Issues," an oral history conducted in 1998 by Denise Sherer Jacobson, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000.

Copy no. /

Cataloguing information

O'TOOLE, Corbett (b.1951)

Leader in Disabled Women's Community

Advocate for Disabled Women's Rights and Health Issues, 2000, xx, 184 pp.

Contracting polio, 1952, family and childhood, Fitchburg State College, Massachusetts, 1969-1973; Center for Independent Living, Berkeley, 1973-1976; organization of disabled women's groups; Rehabilitation Act of 1973, Section 504 sit-in; Keys to Introducing Disabilities in Schools Project (KIDS); advocacy for women, Disabled Rights Education and Defense Fund (DREDF); access to health care for disabled women; adoption of a child with cerebral palsy, reflections on parenting and education; disabled lesbian issues, contributions of lesbians to disability rights movement; United Nations Conference on Women, Beijing, 1995, international issues for women with disabilities.

Interviewed 1998 by Denise Sherer Jacobson for the Disability Rights and Independent Living Movement Oral History Series. The Regional Oral History Office, The Bancroft Library, University of California, Berkeley.

ACKNOWLEDGMENTS

The Disability Rights and Independent Living Movement Oral History Series was funded primarily by a three-year field-initiated research grant awarded in 1996 by the National Institute on Disability and Rehabilitation Research (NIDRR), an agency of the United States Department of Education, Office of Special Education and Rehabilitative Services. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agency.

Special thanks are due to other donors to this project over the years: the Prytanean Society; Raymond Lifchez, Judith Stronach, and Dr. Henry Bruyn; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project.

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SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbcuts on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been

time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

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April 1999

SERIES HISTORY--The Disability Rights and Independent Living Movement
Oral History Project, by Ann Lage and Susan O'Hara

Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The

personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C, was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to

other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

Special thanks are due to donors to this effort over the years: the Prytanean Society; Raymond Lifchez and Judith Stronach; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project. The Bancroft Library's three-year Disabled Persons' Independence Movement Project, of which these oral histories are a part, was funded by a field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Ann Lage, Project Coordinator
Susan O'Hara, Historical Consultant

Regional Oral History Office
The Bancroft Library
University of California, Berkeley
September 1999

August 2000

Disability Rights and Independent Living Movement Oral History Series
The Formative Years in Berkeley, California

Single-interview volumes

- Mary Lou Breslin, *Cofounder and Director of the Disability Rights Education and Defense Fund, Movement Strategist*, 2000.
- Joel Bryan, *Founder and Director of Disabled Students' Services, UC Riverside and UC Davis*, 2000.
- Kitty Cone, *Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977, 2000*.
- Charles Grimes, *Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967-1990s, 2000*.
- Deborah Kaplan, *National Policy Advocate and Leader of Disability Rights Organizations, 1976-1990s, 2000*.
- Johnnie Lacy, *Director, Community Resources for Independent Living: An African-American Woman's Perspective on the Independent Living Movement in the Bay Area, 1960s-1980s, 2000*.
- Joan Leon, *Administrator at Berkeley's Center for Independent Living and the California Department of Rehabilitation, Cofounder of the World Institute on Disability, 2000*.
- Susan O'Hara, *Director of the UC Berkeley Disabled Students' Program, 1988-1992, Coordinator of the Residence Program, 1975-1988, and Community Historian, 2000*.
- Corbett O'Toole, *Advocate for Disabled Women's Rights and Health Issues, 2000*.
- Zona Roberts, *Counselor for UC Berkeley's Physically Disabled Students' Program and the Center for Independent Living, Mother of Ed Roberts. Appended: Jean Wirth, Counselor at the College of San Mateo and Early Mentor to Ed Roberts, 2000*.
- Susan Sygall, *Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues, 2000*.

In Process, single-interview volumes:

Judy Heumann, Deputy director of the Center for Independent Living, cofounder of the World Institute on Disability, assistant secretary of the U.S. Department of Education. (in process)

Arlene Mayerson, Directing attorney, Disability Rights Education and Defense Fund. (in process)

Pat Wright, Director, Governmental Affairs Office of the Disability Rights Education and Defense Fund, strategist for the Americans with Disabilities Act. (in process)

Multi-interview volumes:

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S INDEPENDENT LIVING MOVEMENT, 2000.

Edward V. Roberts, *The UC Berkeley Years: First Student Resident at Cowell Hospital, 1962.*

James Donald, *Student Resident at Cowell, 1967-1968, Attorney and Deputy Director of the California Department of Rehabilitation, 1975-1982.*

Cathrine Caulfield, *First Woman Student in the Cowell Program, 1968.*

Herbert R. Willsmore, *Student Resident at Cowell, 1969-1970, Business Enterprises Manager at the Center For Independent Living, 1975-1977.*

Billy Charles Barner, *First African American Student in the Cowell Program, 1969-1973, Administrator in Disability Programs in Los Angeles.*

John "Jack" Rowan, *Student Resident at Cowell, 1971-1973, and Chair of CIL's Board of Directors, 1976-1982.*

Peter Trier, *Student at Berkeley: Transition from the Cowell Hospital Program to the Residence Halls, 1975.*

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM: KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS, 2000.

Henry Bruyn, *Director, Student Health Services, 1959-1972.*

Edna Brean, *Nurse Coordinator, Cowell Residence Program, 1969-1975.*

Lucile Withington, *Department of Rehabilitation Counselor, Cowell Residence Program, 1969-1971.*

Karen Topp Goodwyn, *Department of Rehabilitation Counselor in Berkeley, 1972-1983.*

Gerald Belchick, *Department of Rehabilitation Counselor, Liaison to the Cowell Program, 1970s.*

John Velton, *Department of Rehabilitation Administrator: Providing Oversight for the Residence Program, Fostering Career Placement and Computer Training, 1970s-1980s.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY VOLUME I, 2000.

Herbert Leibowitz, *Research and Training Specialist for the Rehabilitation Services Administration, 1971-1990.*

Mary Lester, *Grant Writer for the Early Center for Independent Living in Berkeley, 1974-1981.*

Bette McMuldren, *Assistant to Judy Heumann and Grant Writer at the Center for Independent Living, 1975-1980.*

Kenneth Stein, *Public Information Coordinator for the Center for Independent Living and Participant/Observer of the Disability Movement.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II, 2000.

Carol Fewell Billings, Attendant and Observer in the Early Days of the Physically Disabled Students' Program and the Center for Independent Living, 1969-1977.

Michael Fuss, Attendant for Cowell Residents, Assistant Director of the Physically Disabled Students' Program, 1966-1972.

Linda Perotti, An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME III, 2000.

Eric Dibner, Advocate and Specialist in Architectural Accessibility.

Hale Zukas, National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV, 2000.

Janet Brown, Student Member of the National Federation of the Blind and First Newsletter Editor for the Center for Independent Living, 1972-1976.

Phil Chavez, Peer Counselor at the Center for Independent Living, 1970s-1990s.

Frederick C. Collignon, UC Professor of City and Regional Planning: Policy Research and Funding Advocacy.

Hal Kirshbaum, Director of Peer Counseling at the Center for Independent Living.

Michael Pachovas, Berkeley Political Activist, Founder of the Disabled Prisoners' Program.

Raymond "Ray" Uzeta, Independent Living Centers in Berkeley, San Francisco, and San Diego: Perspective on Disability in Minority Communities.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME V, 2000.

Jacquelyn Brand, *Parent Advocate for Independent Living, Founder of the Disabled Children's Computer Group and the Alliance for Technology Access.*

Doreen Pam Steneberg, *Parent Advocate for Educational Rights for Children with Disabilities.*

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS, 2000.

Cynthia Jones, *Mainstream Magazine Editor and Publisher.*

William Stothers, *Journalist and Managing Editor of Mainstream Magazine.*

UNIVERSITY ADMINISTRATORS RECALL ORIGIN OF THE PHYSICALLY DISABLED
STUDENTS' RESIDENCE PROGRAM, 1987.

Arleigh Williams, *Recollections of the Dean of Students.*

Betty H. Neely, *Recollections of the Director of Student Activities and Programs.*

In Process, multi-interview volumes:

Neil Jacobson, *Cofounder of the Computer Training Project and Cochair of the President's Committee on Employment of People with Disabilities.*

Scott Luebking, *Cofounder of the Computer Training Project, Specialist in Accessible Technology. (in process)*

Maureen Fitzgerald, *Early Deaf Services Programs at the Center for Independent Living. (in process)*

Anita Baldwin, *Deputy Director of the Center for Independent Living, Early 1980s: Observations of Blind Services and Staff Strike. (in process)*

Joanne Jauregui, *Activist in the Deaf Community: Deaf Services at Center for Independent Living. (in process)*

VIDEOTAPED INTERVIEWS:

Mary Lou Breslin, Kitty Cone, Neil Jacobson, Joanne Jauregui, Deborah Kaplan, Johnnie Lacy, Joan Leon, Susan O'Hara, Zona Roberts, Ken Stein, Herb Willsmore, Hale Zukas.

INTERVIEW HISTORY--Corbett O'Toole

Corbett O'Toole was invited to participate in the Disability Rights and Independent Living Movement Oral History Series because of her leadership in promoting the international empowerment of women with disabilities. With her involvement with the disabled women's rap group in Berkeley in 1974, the Center for Independent Living's KIDS (Keys to Introducing Disability in Schools) Project in the late seventies, the Disabled Women's Educational Equity Project in the early eighties, and the United Nations Conference on Women in Beijing in 1995, Ms. O'Toole's focus has been to develop global networking among disabled women to deal with issues they face in the political, social, and economic spectrums around the world. In the 1990s, Ms. O'Toole founded the Disabled Women's Alliance.

Ms. O'Toole's six interview sessions from September, 1998, to November, 1998, took place in the interviewer's Oakland home office. The sessions lasted from one and a half to two hours. Both interviewer and interviewee have known each other socially for more than twenty years. The highlights of the interview include Corbett's recount of her early years spent in Boston and growing up with polio (which she contracted at the age of one year), her account of working and playing in the free-flowing environment of the early Center for Independent Living, her detailed eyewitness participation in the 504 sit-in and the effects of its aftermath which created a growth of new community programs.

Corbett candidly discusses her lesbianism, as well as the health and sexual issues of the disabled gay and lesbian population. The interview poignantly covers Corbett's adoption in Japan of her daughter Meecha, who has cerebral palsy. She also offers vivid descriptions of sharing profound experiences with disabled women from all over the world.

The transcript was lightly edited by the interviewer and reviewed by Corbett who made only minor corrections for accuracy and clarity. Interview tapes and associated papers have been placed in the Bancroft Library.

Denise Jacobson
Interviewer-Editor

July 18, 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Corbett Joan O'Toole aka Katherine

Date of birth Aug 28, 1951 Birthplace Boston, Mass.

Father's full name Joseph Leonard Corbett

Occupation firefighter Birthplace Boston, Mass

Mother's full name Margaret Mary Farren Corbett

Occupation home maker Birthplace Boston, Mass.

Your spouse Allison Ann Brown

Occupation Researcher Birthplace Chicago, IL

Your children Mitsuko "Meecha" Bregante Corbett

Where did you grow up? Boston, Mass

Present community Berkeley, CA

Education B.S. Special Education

Occupation(s) educator, filmmaker, trainer, conference organizer, lecturer

Areas of expertise disabled women, disabled girls, education, feminism, lesbians, parenting with a disability, networking

Other interests or activities singing, knitting,

Organizations in which you are active Disabled women's Alliance, Society for Disability Studies

INTERVIEW WITH CORBETT O'TOOLE

I EARLY YEARS, FAMILY, DISABILITY, EDUCATION, 1951-1973

[Interview 1: September 3, 1998] ##¹

Birth and Family

Jacobson: Corbett, let's start with where and when you were born and tell me about your family background.

O'Toole: Okay. Well, I was born August 28, 1951, in Boston, Massachusetts. I'm the oldest child of Margaret Farren Corbett and Joseph Leonard Corbett and both of them were children of Irish immigrants. All four of my grandparents were Irish immigrants and all of them had immigrated to the Boston area. And my parents married when my mother was twenty-five and my father was twenty-six and I was born a year later.

Jacobson: And you have siblings?

O'Toole: Yes, [laughs] after me there were a lot of kids kind of right in a row--nice, good, Irish Catholic family. I'm the oldest of five kids. My sister Susan is a year younger than me, so she was born in '52. My brother Stephen was born in '55. My sister Patricia was born in '56. And my baby sister Ann was born in '62--I'm eleven years older than her, I have to do the math--'62.

Jacobson: What were your parents' occupations?

O'Toole: Well, before my parents were married, my mother worked for the phone company. She had actually had a full scholarship to college in Greek and Latin, but was not able to take it because of World War II. She sort of got dissuaded--you know, it was one of those--she had four brothers and the money for school

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

was saved for the boys. My grandparents didn't have very much money and so she was actually kind of a frustrated scholar--a woman that really wanted to be an academic and wanted to have a college education and wasn't able to because of the times and because of the role of women at that time.

My father was the opposite. My father hated school, did not do well in school, didn't like to read. The only reason he got a high school diploma was because he went into the navy and, at that time, they were offering a high school diploma--as long as you were age seventeen and if you showed up in the navy, they figured you were going to be dead. So they basically gave him a high school diploma. [laughs] And I mean he liked to read the newspaper and stuff every day, but other than that he didn't really have any kind of academic or intellectual interests.

And when he left the navy--he liked hanging out with a group of men and at that time the navy had been all men, so he just went into the fire department. He took the civil service exam. He liked the idea of civil service. And that's what he did all my life was work two days and two nights a week in the fire department. So I had a father that was around a lot. He was home five days and five nights a week. It was kind of an unusual working class life for him to be around. He worked for the fire department officially and then unofficially--he couldn't sit around five days a week so he always had odd jobs with some small businesses. For a while he delivered things and most of my childhood he installed what's called storm windows which is the outside windows that you added onto the old sash wooden windows for the winter weather. He and a friend had a little business and since it didn't matter what day of the week he worked for the fire department, he could do this job the other days. That's what he did. And by the time the kids started, my mother stayed home and became a homemaker.

Jacobson: And so you come from a middle class background?

O'Toole: No, I wouldn't say it was middle class at all, it was working class. My father was like supporting eight people on \$7,000 a year.

Jacobson: But at that time weren't middle class and working class synonyms?

O'Toole: Oh God, no, Denise. Working class fathers were the guys that wore blue shirts and got dirty at work--they worked with their hands. Middle class fathers were the guys that went to an office and maybe had people working under them and maybe

didn't. I mean if you had people working under you, you were definitely, solidly middle class. But no--nobody on our street--the guy across the street delivered newspapers and the guy up the street worked at a garage and it was all the kind of more service-y type jobs.

And we certainly had a very working class analysis of the world. My father would talk about politics or talk about labor--he was in the labor union because of the fire department--and talk about the working man and all that stuff. No, we very much had both a consciousness and an economic status that was much more working class.

Polio, 1952

Jacobson: Well, what was it like for you growing up in that environment?

O'Toole: Well, I'm not sure how that--I mean, that question sort of ties into some of my disability stuff because I was born in August of '51 and by September of 1952 I had polio. I was maybe a year and a couple of weeks old when I got polio and so I grew up as a disabled person in that environment. You know, from a like lifetime perspective, if people don't know disability--I just always say I've been disabled. If I'm talking with people who know polio, they go, "Well, of course," but if they don't know polio then I explain it--from my identity formation, certainly from my life--by saying that I consider myself as always being disabled.

I was significantly disabled with polio when I was baby. I was paralyzed from my neck down. They put me in a full body cast that had slits on the side and my mother would take me out twice a day and exercise my muscles and then put me back in it. So I laid flat on my back or flat on my stomach from my neck to my toes in a cast from the age of one to the age of two and a half.

Jacobson: Why a cast?

O'Toole: I'm not positive, but I think that the reasoning at that time was that since polio caused atrophy of muscles, that at that young age they were concerned about bones being deformed. They'd figured that you were going to walk eventually and that they didn't want the bones to start to warp just because the muscle was pulling on them. So I think the purpose of the casting was to keep the bones in alignment, to keep the

individual bones straight. That's the only reason I can think of about it. But it's pretty significant that all kids do from one to two and a half is move around and all I was doing was lying there.

By that point my mother had me, then my sister and she was pregnant with my brother. And I think I wasn't out of the cast before she--she was still lifting me while she was pregnant with my brother. That was pretty heavy--a kid plus--and you know in those days it was all plaster casts--plus the exercising, plus, plus, plus--. And there was no day care; everybody took care of their own kids.

When I was two and a half, the doctor said I had to go to a rehab center, so they sent me away to a rehab center for six months. And the rehab center was structured such that--they didn't want kids to cry. It was--I'll think about where it was. And what they did was to limit family visits to thirty minutes once a week, so for thirty minutes once a week, my parents could come to visit on Sunday afternoons. I have a snapshot of that. Otherwise they couldn't come, so for six months I was in this institution with--it was primarily an adult facility.

But it was where I learned to walk, where I got my first braces. I had two full steel leg braces and, of course, I got the trunk support with a corset. Then when I was three-ish, I was walking well enough that I could come home. And we lived on the second floor so I could do the stairs. I came home with crutches, braces, a corset, and night casts. So that's when I returned home--at three.

By then my brother had been born and my mother was pregnant with my sister Patricia. So that's sort of the background of how it was growing up with my family--with some of the physical context.

Public School Hurdle

O'Toole: My parents--my mother, particularly--really thought a lot about the options that I was going to have as a disabled kid. I was their oldest kid and we certainly lived in a neighborhood where there were plenty of schools. There were two different elementary schools within walking distance and my mother thought about what would happen for me in terms of school. She talked to people about the options for disabled kids.

In Boston one option was to send me to a school called the Industrial School for Crippled Children--that was the official name of it. It was across town. They bused kids in from the larger Boston metropolitan area. And my mother talked to some people about it. Basically it was a warehouse for kids that local schools were refusing to accommodate, but the kids, whose parents wanted an education for them, would get shipped there. It wasn't a public school in the sense that it didn't have a quality education, it didn't have science labs, it didn't have kind of life [wry laugh]--it was a quasi-institutional environment. My mother decided, no, that she was going to send me to public school.

You know, she grew up in FDR [Franklin Delano Roosevelt]--in her consciousness, even though everyone pretended he wasn't disabled, they knew he was disabled and had polio. In fact, when I was seven we went to the world premier in Boston of Sunrise at Campobello as part of the March of Dimes telethon bank. [laughter] So, early on my mother decided that she had a choice to make. And my father could have gone either way, but my mother said she had a choice to make about what kind of life I was going to have and decided very much to put me in the mainstream of America. She said, "You know, if FDR can do it, you can do it." And he had lots more money than we did, but the thought was that I was not going to be well-served by being in an isolated, segregated, separated environment--that it wasn't going to help me learn or grow or learn how to deal with the real world. She saw me in the real world.

And so her first big hurdle, actually, was public school. She called the public school and they told her in the spring to come register for the fall. So she registered. She called them and said, "My daughter has polio, she walks with crutches, blah, blah, blah."

At that time the kindergarten classroom was in the basement with mentally retarded classrooms. The other classrooms were upstairs. My mother has told me this story--the kindergarten teacher freaked out about having a handicapped child in a regular classroom. She went off to Tufts University, which was a local educational institution, and took a class over the summer called "A Handicapped Child in a Regular Classroom"--or probably in those days it was called in a normal classroom--to prepare for my arrival.

So, I show up quite unknown to all of this stuff--doing okay. My mother had really worked hard with me on independence and I was totally taking care of myself--could go to the bathroom by myself, take a bath by myself, put my clothes on

and off--you know, the kind of stuff that you need to know in order to survive. So I went to school and I was functioning pretty independently and pretty much expected to just do whatever I was doing. The teachers were a little surprised by that, but kindergarten was rather uneventful for the first month or so.

Then one day I happened to arrive at the painting easel. My mother, at that point, had four kids and I was always competing for my Mom's attention. She was distracted and she was busy, she was taking care of four kids and cooking three meals a day. We were living with my grandmother and so a lot of stuff was going on. So I bring home art work and she'd go, "Oh, nice, thanks," and put it down and that was the end of it, so one day I get to the easel and there's only a thing of red paint, so I paint this picture and it's all red. And I bring it home to my mother that day and my mother says, "Oh! Red is my favorite color! I love this picture!" and she puts it on the fridge. So I thought, I get it. My mom likes red. If I bring home red, good things are going to happen. [laughter] So for a week, I'd go to school and paint a red picture, every day.

Next thing I know my mother gets a phone call from the school: "We have to talk about your daughter." And so my mother goes trotting in--my mother at this point--what is she? thirty years old, she's got four kids, she's never been to a parent-teacher conference in her life. Her parents are immigrants, her mother is not very helpful about preparing her for what to expect, so she troddles down to the school teacher and the school teacher says, "I'm very concerned about your daughter." And my mom says, "Well, why? She seems like she's not coming home with major scars or anything. [laughs] What's the problem?"

And the teacher says, "Well, you know, she colors a lot of paintings with the color red." (And this was the fifties when color theory was very important.) She told my mother, "You know, in the class I took over the summer--'The Handicapped Child in the Normal Classroom,'--the color red is a sign of immaturity. And these children tend to be immature, that's pretty much expected. So, we have a problem that your daughter is immature and she's in this class and she's painting with the color red."

Well, my mother was devastated--number one, because she loved the color red and that meant of course that she was immature--so she went home crying to her mother. And her mother basically sat her down and said, "Peg, get a clue.

[laughs] The teacher doesn't have any kids. Your kid's doing fine. Look at your kid in relation to other kids and don't worry about it." So the rest of kindergarten my mother basically ignored the teacher and the teacher basically ignored my mother and I got through kindergarten okay.

When the kindergarten year was ending, the principal went to my mother and said that I was not going to be allowed to continue in public school because there were stairs. You had to go upstairs to the first floor to get to the first and second grades. They had decided it was too dangerous for me to do that, and that it was inappropriate for me to be in public school anyway. They felt they didn't have to accommodate a disabled kid, and that there was the Industrial School for Crippled Children if my mother really thought that having an education was important.

Catholic School

O'Toole: So my mother went home and reviewed her options and tried to figure out what was going on. We were members of the local Catholic church that was about a mile away and they had a school. They had first grade to twelfth grade school--what they called a parish school--attached to the church. And there was a group of nuns that lived there and were the teachers. So my mother called up the local Catholic school and asked, "When are you enrolling for the fall, and what age do kids have to be?" She found out what their schedule was and showed up--had learned a lesson: did not tell them I was disabled, did not warn them I was coming. They told her, whatever--August 15--you come and register your kid for first grade and school starts on, whatever--September 10.

So August 15 she dragged me in, my siblings in tow, and said, "Here she is." And they mumbled in shock, and she said, "I'm a Catholic, I belong to this church, you take children who belong to this church, she is my daughter, this is a school, she's ready for first grade."

Of course everything in this school was upstairs; there wasn't even a basement level. So that's how I got into school and that's the reason all of the kids in my family ended up in Catholic school instead of free public school--at that point, actually, Catholic school was also free, but the public school was much closer. For about a year my mother walked me to school every day because for first grade I was the only kid in

the family going to school. By second grade my sister and I could walk together.

Jacobson: You walked a mile?

O'Toole: Oh, yes. There was no other way--my mother didn't drive. She didn't learn to drive until, God, I was almost in high school. Somebody had to walk me, so my grandmother would stay with the younger kids and my mother would walk me to school and then walk home and did it every day for a year. And finally what I think happened, they started a community physical therapy program where they brought physical therapists into regional neighborhoods so you didn't have to go into the hospital for your physical therapy. They had some money for a few years--well, with the polio epidemic, there were so many kids. My mother met some local parents there who said don't you know about the free cabs? She goes, "What!" The school district actually would bus kids for free, not just to the Industrial School of Crippled Children but also to local public schools. She found out that was available, so by second grade I was taking a cab to school every day. The public school district paid for it. And that's how I went back to school every day for the rest of the time I was in school until I graduated.

Jacobson: How did you get along with the other kids in school?

O'Toole: I remember the first couple of years, especially Catholic school, being a little rough because I had crutches and a full-leg brace on my right leg and a half-leg brace on my left leg, at that point. All the girls wore skirts. You couldn't wear pants to school. In fact, at Catholic school we wore a uniform, which was a jumper.

I remember playground stuff being a little hard, especially because we were outdoors in the winter and jump rope was what the girls did. Catholics are not very big on P.E., [laughs] so there wasn't much in the way of--there was no sports, there was no nothing, it was just, "Okay, here's fifteen minutes. Go in the yard, freeze to your death, and don't come back in for fifteen minutes." That happened at recess and at lunch, so I remember the playground stuff was a little rough.

But other than that it was just school: there were fifty kids--five zero--fifty kids in each classroom. There were two first grades, two second grades, two third grades, and it was basically a sit down, shut up, and fold your hands education. It wasn't particularly interactive, it wasn't particularly child-focused; it was just sit down and we're going to tell you what you have to memorize and then you memorize it.

It was the kind of education that didn't really allow a lot of room for discussion about too much of anything and so the kids and I kind of just learned to be with each other. And by the time we hit third grade, basically those were the kids I went through twelfth grade with, so when we hit third grade we were all used to being with each other. Everybody had figured out, you know, this kid didn't have a mother or that kid, that kid lived with a grandma, and I was just one of the kids, in terms of this is what was different about me.

And it was a little weird for me because Catholic school was so far away and most parents didn't sent their kids from very far away. Most of the kids in the Catholic school lived within walking distance, where basically they could either have gone to the local public school or the local Catholic school--they were kind of equally distant. There weren't that many kids that came from as far away as I did, so basically there was never anybody in my neighborhood that went to my school other than my sisters and brother. So I had neighborhood friends and then I had school friends and they were really different people. Because the school kids--in the elementary grades you don't really go a mile by yourself just for social stuff. The school kids lived and hung around the school and the neighborhood kids lived and hung around in the neighborhood and so they were really pretty different crowds of kids--not so much types of kids, but just different. I just had two different circles of friends.

Grandmother's Death--Family Disruption

Jacobson: You went to the parish school through--

O'Toole: Through twelfth grade.

Jacobson: And then what?

O'Toole: Then, well, kind of an earlier question you wanted to ask was how were things with my family. Things seemed to me when I was a little kid to be pretty okay. You know, there were a lot of kids, there was a lot going on, but the family seemed pretty functional, like it seemed everything was okay. My father would get up and go to work every day. My mother would clean the house every day. My grandmother, who was actually a maid, would actually get up and go to work every day as well. We all shared the top two stories of a three-story house together. There were eight of us--well, by then it was seven of us--but

by the time I was eleven there was eight of us because my baby sister was born.

But when I was twelve my grandmother died, and what became clear at that point was that my parents had sort of learned to act the roles, to do what they were supposed to do as grownups as long as my grandmother was kind of around. She didn't really talk to them, but they knew what their jobs were because, you know, she sort of helped them learn those jobs and then they just did those jobs. The minute my grandmother died things in my family just really fell apart. My parents were just not able to function as well. My mother started drinking, my brother started drinking--he actually didn't start drinking for a few years--my sister who's a year younger than me started dating and staying out with boys, and my father started incesting the girls in the family.

So things in my family--it's like when you're someplace and you're a kid and there's grownups around. You sort of obey the rules because you know the grownups are there, and when the grownups start to leave and say, Now, be good, but then they're not around anymore. Well, it was like that when my grandmother died--like the grownup in the family had left--even though it didn't look like that from the outside. When I think back about what happened from the time I was twelve until the time I was eighteen, my family fell apart pretty hard. And both the adults and the kids--everybody--lost their role and lost their way.

Jacobson: How did you deal with that?

O'Toole: I don't know. I mean, what the polio had taught me was that I could get through anything. I had had a full body cast for a year and a half, I had been sent away to an institution for six months--and the thing I think was hardest for me about both of those was everybody saying that there's nothing going on, it's no big deal. Everything's fine. And I was freaking out, but there was no space to express it.

Then when I was seven, nine, eleven, sixteen, I had surgeries, which for me as a kid felt like somebody's signing off your rights to protect your body. They say, "Hey, here, cut her; sure, make her hurt." And I'm being told to shut up because, "it's for your own good." I'm not saying that, in the long run, I wouldn't have made the same decisions, but as a kid you don't have any choice about those decisions. So what I learned from that was that I could get through anything--I could get through separations of my parents, I could get

through being alone, I could get through being hospitalized, I could get through surgeries.

Summer Camp Refuge

O'Toole: I also, when I was seven, started going to a camp (Camp Caravan in South Royalston, Massachusetts) for disabled kids. A man who had a physical disability ran the camp. He and his daughter both had had polio and he had started a camp for her. By the time I met her she was an adult--she was one of the counselors at the camp. It was a very structured camp. One of my adult friends who went there fourteen years later called it a fascist summer camp because it was very--you knew every minute of every day what you were going to do, what you were going to eat. I loved it. I felt so safe and so protected and it was wonderful to be with other disabled kids because it was this whole range. I jokingly say that anybody who ever talked with a social worker could go to this camp. There were kids with Down's Syndrome, kids that were deaf, kids that were blind, other kids with polio, kids with CP, kids with osteogenesis imperfecta--there was just this whole range of kids that showed up.

There were ten of us to a cabin and usually fifty girls and forty boys at this camp with a minimum stay of one month. You could stay for one month or two months and parents were not allowed at the camp so you didn't have any kind of craziness about adults coming in or out, or kids and presents--I mean, none of that stuff--so it was wonderful!

It was big. It was out in the country. There was a whole woodworking building, a ceramics building, an arts and crafts building. Then there was a nature lodge and we went out on hikes and we went fishing. And I learned to shoot an arrow, shoot guns, and play basketball. I mean, it was stuff I never got to do--certainly not as a cripple--in the city. So from camp I learned that the world can be a safe place. Camp was never an unsafe place--camp was always really safe, no matter what. I went there for a number of years--for probably eight years--and it was always a place I loved to go. I always felt safe and very protected. Also challenged--really challenged. There were always new things to learn and new things to do and new ways to be. I loved camp. So that gave me an experience that the world could be a fun and challenging place and that being away from home was a good thing.

Home was showing me that sometimes things didn't stay the same. And things that people called love--all through my mother's drinking she's saying, "I love you, I love you;" the whole time my father's incesting: "I love you, I love you."

When things degenerated in my family, I felt like I had a couple of choices. I was sixteen and I remember just sitting down. I had talked to my mother about the incest--my mother had told me (a) it didn't happen, and (b) if it did happen, it wasn't really important. And she told me that the same thing had happened to her in her house with her uncle--when her uncles would come over off the boat.

So she--she was drinking by this point--but she basically said she wasn't going to take care of this. My father wasn't going to take care of this--my grandmother was dead, and so at sixteen I sort of sat myself down and said, "Okay, what am I going to do?"

I didn't think I had enough street smarts to be able to leave. The school I was going to didn't have a lot of options. I had tried the year before--when I was in ninth grade, I figured that public school would have more options, so I spent a year talking my mother into letting me transfer to public school for tenth grade. And she said, fine, she would do that. And then the summer--

Options In Adolescence

Jacobson: We were talking about you making decisions about what you wanted to do.

O'Toole: Yes, and the year I was in ninth grade, I decided public school would probably have some more options. A girl I had gone to school with through eighth grade had left and really helped me --I would hang out with her and her family. They helped me realize that there were many more opportunities in public school--even though the public school was farther away than my Catholic school. Because we lived on the edge of a town--we lived on a border between Medford and Somerville--I grew up in Medford, Massachusetts, and we lived right on the border of Somerville, but anyway, because of the cab, it didn't really matter.

But the summer between my ninth grade and my tenth grade year, some kids got into the school and burnt it half to the

ground, so for the fall for tenth grade it was going to be everybody was on half sessions. You know, half the building was burned, the labs were burned, all this stuff was burned, and my mother said forget it, the deal's off. She said Catholic school would give a better option than this kind of half school and everybody was crazy in public school, double sessions. And so I was stuck in Catholic school.

I didn't really know a lot of people, so I didn't have a lot of options in terms of going away from home or doing other kinds of stuff. In those days, we didn't talk to--I had a lot of aunts and uncles I was close to, but we didn't talk about this kind of stuff and you certainly couldn't say, "Can I come live with you?" I mean, none of that stuff would have--because that would have meant busting my parents and their dysfunction and they didn't want to be busted and all that stuff. I didn't feel like I had an option to live on the street; I didn't feel like I had the skills. I didn't have any options about going away to go to school. We didn't have any money and I didn't know about any programs. Now I know about programs, but then I didn't know about any programs.

So I decided two things. I decided, number one, I would just have to stick it out until it was time--get good grades and stick it out until it was time for college, but make sure I could go to college, and make sure I went away to college. And secondly, that I would start to work outside the home and get some money and just be able to just feel like I had something to do besides go to school and come home and sit home. My younger sister Susan, who's a year younger, had already been dating and my mother wasn't willing to buy her the newest clothes, the fanciest stuff, so she had started working. So I saw the freedom that it gave her to be out of the house a lot more, be away from my father, just kind of come and go more as she pleased, and I thought, Well, this is a good thing. So that's how I got through high school. I worked. I would work after school--

Jacobson: What kind of work?

O'Toole: I started out working at the neighborhood pharmacy--in those days they had soda fountains--working at the soda fountain and just ringing up local utility bills and stuff. And then I got a job at the YWCA in Boston working in a kids' program. And that was great because college students ran it and I got to meet other kids--high school students who were my age. We were all on site counselors. That was a blast. That started to get me out of the house and meeting some people.

Jacobson: How did you get there?

O'Toole: To the Y?

Jacobson: Yes.

O'Toole: I don't have any memory of that. I don't know whether-- certainly probably didn't see it in the newspaper. I don't know. The truth is I don't remember how I got that.

Jacobson: I mean, by bus?

O'Toole: Oh, I'm sorry, oh, how I physically got there. Yes, it was in Boston. Because she didn't drive, my mother had us all learn to use the buses when we were really young. Boston has a really extensive bus and subway system so it was pretty easy to get around. I remember like at fourteen going into Boston by myself by taking a bus--the bus was two blocks away--to the train and taking the train into--we called it into town, downtown. Then I'd go shopping or whatever and turn around and go back, so I knew how to do that pretty young. So the idea of working in Boston was pretty easy in terms of just transit--it was just public transportation. In those days it was probably like a nickel or something a ride, so if you're making like three bucks an hour, then a nickel's kind of nothing to get to work.

Then in those days Department of Rehabilitation paid for college, you know, if you had any brains, so I knew I could go to school.

The College Track, 1968

Jacobson: Now, how did you find out about college?

O'Toole: Probably--well, two things. One is that some of the kids at camp were looking at that, but more importantly, the nuns, the teachers at school knew about Department of Rehab. They knew that if you had a disabled kid, you sent them to camp, or you sent them to Department of Rehab and they would help them go to college or pay for job training. Since I was doing fine in school--I was on the honor roll most of the time, you know--they figured that I was definitely on a college--the whole school was college-track oriented. So they just sent me to DR when I was sixteen and DR asked what do you want to do, and told me come back next year. They said, "Get accepted to the

right schools and we'll do the paperwork for you and we'll pay for it."

The DR counselor and I had this kind of wild time because she was really wonderful and she was trying to send me to a good school. I wanted--one of the jobs I had in high school was a Saturday job working with retarded adults that I really liked and so I decided, "Oh, I can be a special education teacher and help those poor unfortunate people that are more poor and unfortunate than me." Well, in those days, there were three girl jobs: one was to be a secretary, one was to be a nurse, and the other was to be a teacher. That was pretty much it. I mean, all the women I knew did those kinds of jobs. I definitely did not want to sit behind a desk, in fact, I purposely did not learn to type in high school because I didn't even want to think about those kind of jobs, even as summer jobs. I thought they were too boring.

I had thought about being a nurse and then I had a surgery when I was sixteen and saw that basically all they did was empty bedpans and take orders from male doctors. I decided that was probably not something I wanted to do, either. Who knew about my physical stamina--but the job description just didn't seem--when I saw it up close and personal, I was less interested.

So that left teaching. I was okay hanging out with retarded people and so I figured I could teach. I could teach school. It was a somewhat autonomous job: you had your own class, you got to make decisions.

But in Massachusetts at that time, there were only five schools in the whole state that taught special education. Three of them were in Boston. Some of them were way across town and in the snow would have been horrific to go to--like Boston University, Boston College, or Lesley--and I could have gotten into Boston College which academically is a very good school. Whenever I talked to my father about that, he said I'd have to live at home, even though DR would pay for the dorms. I wasn't gonna. I mean, the purpose of going to college was to get away from home, not to stay home. So those three schools were out.

And that left two other schools: one was a state college that had once been a teacher's college and one was an all girls' Catholic school. And the all girls' Catholic school was out. Twelve years of Catholic education and I had had it. So that left the state school. And the poor DR counselor was having this conversation with my father and me sitting side by

side, trying to convince me to go to Boston College and how DR would pay. The tuition disparity was enormous, but they said how it wasn't a matter of money; they would pay to send me to a decent school because I seemed like a reasonably intelligent kid. I had good grades and wouldn't I really rather go to a good school and get a good education? And I'm fighting with them to go to this middle of the road, middle of nowhere teachers' college.

Jacobson: What year was this?

O'Toole: Well, I graduated high school in '69, so I was having this fight with them in '68. And what can I say to this woman: See this guy who is sitting next to me? He's incesting me. I have to get away from him. [laughs] What are you going to do, you know? So I went to Fitchburg State College in the middle of Massachusetts, spent four years there and got a degree in special education in 1973.

Two Separate Realities

Jacobson: Now, did you, when you were growing up, have a sense of who you were as a disabled person? Did you feel like your disability limited you?

O'Toole: There's a lot of stuff for me about image of disability and my disability. I felt very split in my life and certainly in my body. I felt like I had this one life where I was at school and in a family and just a person who was doing regular stuff and just kind of a member of the community. And because both in my family and in my school people had known me for a long time, the issue of disability didn't really come up in a very direct way. I had gotten them used to what I could do and they knew not to ask me to do other kinds of things. So we sort of had, if you will, this gentleman's agreement where my disability just didn't get talked about pretty much either at home or at school.

Then I had--actually there are three parts--but then I had this public life where it was like me walking down the street, whether I was going to school or going in the store, or whatever. I lived in a very ethnically strong neighborhood. Almost every single house--certainly on our street and pretty much all the way from my house to my school--everybody's grandparents were from either southern Italy or from Ireland, so there were people for whom village was a very alive concept.

And on almost a daily basis between my house and wherever I was going, someone would stop me, a neighborhood person--because I was walking with crutches--have the following conversation with me. They would say to me, "What's wrong with you?"

I would answer, "I have polio." And they would ask, "How did you get polio? Didn't you take this vaccine?" It was after '56 or '57, which is when I would be out walking by myself. I would explain that I got it before the vaccine was available.

And then they would start telling a story that had one of two or three themes. One theme was, "That's really awful and can't they do anything for you?" Another theme was, "You should follow my aunt/cousin/sister/brother/father's advice because they did 'X'." Now in those days it wasn't new age remedies, in those days it was a surgery or a therapy--you know, whatever. And so the gist of the conversation was, "Your disability is pretty unacceptable, and it's making me uncomfortable"--me, the other person, uncomfortable--"and I want to tell you what to do so that you can get rid of this disability."

My mother modeled the way I had to handle these conversations because if they happened with her, she made me stand there and talk to the people and answer them politely. And they would always end with, "I'll pray for you," or "I'm really sorry for you," or something along that line. I hated those conversations. And I once wrote about this and it was Jennifer [Bregante] who said to me, she thought it was something that had only happened once, that I had just told the story a thousand times. But it happened pretty much every day. When Jennifer finally went back to Boston with me and we walked to the local bus stop and it happened in front of her, she was really dumbstruck by the pervasiveness of this experience.

Anyway, what I learned pretty early on was that I, as a public person--as a person in public--made people uncomfortable. How they interpreted their discomfort was to make me miserable, to say bad things to me, to hurt my feelings, to shame me, to basically single me out as an oddity that was unacceptable and needed to be modified, fixed, or whatever. So that was another reality that was going on.

The hospital was another environment. It was me with the doctors, dealing with the medical condition of polio: being in an environment where my legs were examined by strange men discussing what parts to cut and what parts not to cut. Where I was asked to be compliant, not only with their treatment and

their discussions with me, but with their follow-up care. They'd say, Go home and do these exercises--stretch your foot this way, wear your cast like this, wear your braces every day. There was a certain part of my life which was about agreeing to a medical regimen and agreeing to a medicalization of my body and of my life.

And then there was a fourth part of my disability where I went to camp and I was with people that more or less looked like me. I mean, because we were all disabled--we were all in this whole spectrum, but I was with people that pretty much looked like me, pretty much acted like me and we were just kids, where our disability was like a normative factor, but where we were just kids together.

So I learned at a pretty early age to have what I call the "neck up thing," where from the neck up I existed as a person, but pretty much from the neck down, I didn't exist. When I talk to people and we joke around about "when did you start masturbating?" It's like, I didn't even know I had a body until I got into my twenties. Because, you know, forget sex! The whole experience of my body was something that other people touched, other people manipulated, other people could hurt. Adults would sign off and allow other adults to do things to me that I didn't want and that were painful. It was a cause of shame and it was like a public stigmata of--a mark. It gave people who didn't know me at all the right to make decisions and interfere in my life, either in a casual way, such as the strangers on the street would, or in a direct way, like the doctors. And I couldn't get rid of it! I couldn't hide it, or get away from it, or make it invisible.

So all of those things--I know it's kind of a complicated answer to your question, but I mean all of those things were at play for me about how it was being a disabled person. So for the most part I created these two identities. I created an identity where I was disabled, but in the disabled environment, it was primarily like a "victim of medicalization" kind of thing, or I was not disabled--that whole kind of "my spirit is free, but my body is chained" mentality. I just had two completely separate realities.

So I'd be hanging out with nondisabled kids and as far as I was concerned, my disability wasn't present. I wasn't there. I wasn't dealing with--I didn't ask to sit down, I didn't ask for accommodations, I just passed. As I got older with my polio, meaning in my childhood, I had less and less equipment. I went from two long leg braces to one long leg brace on my right leg and short leg brace on my left leg by the time I

started school. Then a few years later I got rid of my left leg brace. Then a few years later my right leg brace went down a half. And then by eleven or twelve, after that surgery they took off the brace entirely, so my ability to pass increased with my age. And I went from two crutches to one crutch and finally to a cane. By the time I graduated high school I was using just a cane.

I sort of just bought into this thing that the disability part of my life did not have positive value. It was not a social asset outside of camp, which was nice--I mean, we never went anywhere as a group, so I never had the experience of being in public as a disabled person--it was just by ourselves at camp. Socially it was a major liability. You know, it was certainly a liability for dating in high school and all that stuff, so it became this thing to be hidden.

And I remember a conversation I had with my mother that was very telling for me. I was about twelve or thirteen--somewhere around there--and I had walked to the local bus stop and I had had to cross a major street. And there were people standing at one bus stop as I was crossing to the other one and they stared at me the whole time. I mean, they just looked at me and stared as I walked across the street. At that point I was walking with maybe one crutch and I didn't have any braces. I limped pretty significantly. And they were far enough away that they really couldn't talk to me, but they stared.

I came home and said to my mother, "You know, I really hate it when people stare at me." And her comment was, "Well, why do you think they're staring at you?" but more with the voice of, "They're not." You know, "Why would you think that anybody would be staring at you?" And I said, "Well, because (a) they were staring at me [laughs] and (b) I thought they were staring at me because of my disability." She said to me that I think that everything's about being so different. And it's not about being different. She wasn't even there, but she insisted that nobody was staring at me, and that I always think I'm an individualist but really I'm just one of the crowd. I just had to get used to the idea.

The experience of having a direct reality totally challenged by someone who wasn't even there was really pretty striking to me. I thought, Okay, I get this. My mother and I can't talk about my disability. That's sort of what I got out of it all.

College Experience, 1969-1973

Jacobson: You left high school and went right to college?

O'Toole: Right. Yes, I left. I graduated high school in June and was in college whenever--August or September--you know, whenever it was time to move into the dorms.

Jacobson: And what was that like?

O'Toole: College was kind of interesting in a lot of different ways. It was really good to be away from my parents. That part was very nice. It was very freeing to be away. I liked the structure of living in a dorm. You know, I didn't have to cook for myself, I didn't have to pay the rent, I mean, that was the last time I didn't have to.

At that point the dorms I was living in still had hazing, so it was pretty intense to leave home and right away be hazed. I went through a two-week hazing process as part of the initiation to moving into the dormitories. I thought that was pretty bad.

Jacobson: Can you describe hazing?

O'Toole: Well, how it worked was--it was a high-rise dormitory and on every floor what they would do is all of the new students--all of the freshmen--would be marched out in front of all of the upper classmen every night. And they would stand you in a line and make you do things--make you do stupid things: put toothpaste on your face--which burns actually--and leave it there, or make you sing songs, or make you do stunts or whatever. And this went on for a couple of weeks. And then at the end of it, they had this party and said, "Okay, now you're one of us." And I was like, "Great, I can be part of the abuse team." [laughs] It was not a pleasant experience.

It was nice to be in college. It was nice to be intellectually challenged. I had felt pretty bored in high school and it was nice to kind of have the bar raised a little. And in those days nobody had typewriters--[phone rings--tape interruption]

Jacobson: Okay, we were talking about college and dorm life.

O'Toole: Yes, so the dorms were a little intense at the beginning but after that we sort of settled down. In fact, one of the women that I was neighbors with in college I'm still friends with

now. She's probably the only person that I'm still buddies with.

The campus was not at all accessible. It was relatively flat but the main campus was kind of on a mound. It had two or three outside stone stairs with no banisters to get to everything. At that point I was walking with a cane, so it wasn't the most stable of supports when the ground and everything was not good, and so I spent a lot of time worrying about falling down.

Even though I was in special ed, the first year was just the general ed requirements, so I just took general ed classes. Then in the beginning of the second year, the special ed classes started and the head of the department taught this class called "Introduction to Special Education." And there was me and another woman who was disabled who limped a little--who had a--I don't know what it's called--like a congenital dislocated hip, so she kind of walked on her toe on one side on one foot.

And we were sitting in class and I'm sitting in the back of the class and--the guy's name was William Goldman--he was sitting there and he was talking about different parts of special ed and teaching retarded kids and teaching deaf kids and teaching physically disabled kids. He talked about a woman that had applied to school, a number of years before me--two or three years before I applied--who was physically disabled. I don't know whether she used a chair or just had crutches, but she was significantly physically disabled, and he met with her and he told her that he wouldn't accept her in the program. He told her that the reason he wouldn't accept her in the program was because she would never be able to do teaching of any kind, that it was basically inappropriate for her to think that as a person with a disability she should be in special education. So that sort of set the tone for me of school, of special ed.

So special ed was about us--the able-bodied--telling them--the retarded--what to do and how to do it. It was never about disabled people being any part of that picture. And it was important for this other woman, who had a disability, and me to pretend like we weren't disabled or he was going to throw us out. That was sort of the underlying message--disabled people can't teach. I knew if I wanted to get this teaching credential, which I personally saw as my lifeline, I needed to toe the line and not be disabled. I had to have a marketable skill so that the day I walked out of college I could make money and I would never end up back at my parents' house.

So academically that sort of set the tone for the whole special ed department. You know, I got through school and I did my student teaching and I did all that stuff, but I pretty much hid my disability--which is hilarious in a special education program [laughs] to be intentionally hiding a disability. But that's how I got through it.

Jacobson: And at the time when you were in school it was in the early seventies?

O'Toole: Yes, '69 to '73.

Jacobson: That was the time of civil rights. Were you a part of that?

O'Toole: No, my campus was like an island of ignorance. [laughter] I mean, we had a teacher, actually, who had gone--he was a working class kid from Boston--William Keough--he had gone to Harvard. When Harvard was taking poor white kids (that was their affirmative action plan, was poor white kids), he had gone to Harvard. He had ended up at the Iowa Writers' Program and so he was--he was like a first year, second year. So Dr. Keough had left Iowa and wanted to come back to Boston, which is where he had been raised. He had actually married a woman that was an Iranian princess--somebody that was part of the Iranian royal family. He had gone to Turkey--he jokingly said later, "looking for drugs," [laughs]--but, you know, he had gotten some kind of fellowship to Turkey and married a woman who was from the Middle East who was part of a royal family. He had this fantasy that he was going to come back--figuring it didn't matter if he was stuck in the boonies because Boston was just an hour away--have a full-time job, but still be part of the academic Boston community.

So he came and he had this reader--he didn't want to teach out of this 1950s textbook on English literature, he wanted to teach contemporary stuff--so he brought this like radical contemporary Mario Savio material to a bunch of hick kids whose fathers were firemen, policemen and truck drivers. You know, we weren't doctors' kids or lawyers' kids, we were all pretty poor kids. And he tried to teach English literature with this material and it was a joke. We didn't get--I mean, it was like reading the newspaper; we didn't understand, we just thought it was something that happened someplace else, like Berkeley, but it certainly didn't happen in Fitchburg, Massachusetts, and it didn't have any relationship to our lives. He used that text for one semester and then got rid of it because we were so out of it.

Jacobson: So, when did it all change for you?

O'Toole: Oh, when did it all change for me. Really not until I moved to Berkeley. My life was--it's pretty much the before Berkeley and after Berkeley life. Things back East were about just pretty much surviving.

Jacobson: What year?

O'Toole: I came out here in 1973. I had found a boyfriend in college. He didn't go to my school, he went to a rich kid's school. And he and I had hooked up like my sophomore year. He was a merit scholar in high school and he was going to Holy Cross in Worcester, Massachusetts. I mean, he was going to good schools. He wanted to get a Ph.D. in Chinese studies and he applied, you know, to Harvard, Yale, Princeton, Michigan, Chicago, and Berkeley. The East Coast schools didn't accept him for a Ph.D., but Chicago, Michigan, and Berkeley did. He talked to me about it. And he wanted to get married and I was like, I don't think so, but he said, "I don't know where I want to go. I might want to go to Chicago." I said, "Do whatever you want to do but I'm not leaving snow to move to snow where I don't know anybody. If I'm going anywhere I'll go to Berkeley. If you go to Berkeley I'll go with you because I could leave snow for sun, but I'm not leaving snow for snow."

II MOVE TO BERKELEY, WORK AT CENTER FOR INDEPENDENT LIVING, 1973-1976

Move To Berkeley, 1973

O'Toole: So I had met this guy David Keegan and I wanted to--and I just knew I needed to get out--anything except going back and living with my parents. My teaching credential at that point was a Massachusetts teaching credential but I figured that I could find a job. In those days it was not that hard to find work. So he says he going to either Chicago or Berkeley and I said, "Chicago's a nice place, but I ain't going to live there." Especially because the school was in downtown Chicago and it was hot in the summers in Chicago [laughs]. I didn't really want to be in Chicago and didn't know anybody there. I said that if he moved to Berkeley I'd move to Berkeley with him, but I wasn't going to go to Chicago. So he thought about it and finally decided that he could live with going to Berkeley. So I said, "Fine, I'll go with you." And that's what we did.

We got in his Volkswagen--I mean, his parents hated me. It was funny because his father was a lawyer, his mother was college-educated at a time when nobody was college-educated, or it wasn't really common for women. He was their only son, his mother's pride and joy. She had big hopes for major socialite weddings and stuff. But he had been always in boys' schools and he was kind of a misfit. And at that point Holy Cross was an all male college and he was a social misfit, he didn't have any social skills at all. His mother saw that I was not going to move him up the economic or social ladder. She told him, actually, that I was frivolous and flighty and he should get rid of me. He did not heed his mother's advice, but I knew I wasn't going to marry him, so I wasn't really that worried about what his mother was concerned about. So we packed up a Volkswagen bug with like almost nothing and moved to California--drove to California across country in August of 1973 and landed in Berkeley.

We had been camping across country and got in Berkeley and said, Okay, where's the campgrounds? And everybody at the university laughed at us saying, "What do you mean campgrounds in Berkeley--there's like no place to camp anywhere near here." So we kind of jostled around for a few days and found housing down on Claremont, right where Claremont hits 51st. There's an apartment building next to a porn theater, actually, [laughs] and we moved in, lived there. In fact, one of the things David had brought with him was a bicycle to go back and forth to school and we had one of those "back of the car" bike racks and we actually used that as seating for a very long time. We put a board across it and that was our little visitor's chair. We ate off crates on the floor. And we lived there for a while and eventually got into housing at UC Berkeley over in Albany. But it was the start of me in Berkeley.

Jacobson: So you came to Berkeley and your teaching credential--

O'Toole: Was no good. [laughs]

Jacobson: Was no good. [laughter] So what did you do?

O'Toole: Well, it was an interesting--I mean, I didn't know anybody, I had never been west of New York City, so any part of coming to Berkeley--I just knew it didn't snow here. That was like what I knew about it, is it didn't snow, which was the only reason I said I would come. And I figured it was the coast, I like water, I like coast, so I could deal with coast. It was pretty far away from my parents, I figured it was pretty safe. But I didn't know a soul and David, you know, pretty quickly knew people and had a life, mostly a living-in-the-library life, but he pretty quickly had a life.

I pretty quickly didn't, so I did a couple of things. I looked for work, but everybody and their sister had moved here from Boston or New York and had college degrees. Lots of people had East Coast teaching credentials; the competition for work was very intense at that time because a lot of people had come for the activism and the political work. There were just tons of really qualified people. They knew people because they were part of political movements and they had access to jobs. The baby boomer thing was ending so there weren't a lot of kids in the schools. The schools weren't really desperate for teachers at all, so I started out tutoring a kid, actually, an autistic boy--which slowly turned into a private school teaching job.

When he went into a school program, a private school for kids with severe emotional disabilities, I went with him into

the program. I was his transition into that program and then stayed in the school for about a year and a half.

Disabled Women's Rap Group, 1974

O'Toole: In the meantime, I was looking for something to do. And I was hanging out at the university at the student union building and saw a sign for--at that point there was what was called a women's free school--Breakaway was the name of it. There was a group of women working together, publishing a catalogue twice a year and then you would show up on one Sunday afternoon and sign up for classes and you'd get information about where the class was. There were all kinds of different classes, so they needed help. I needed something to do, so I joined them and helped them with the grunt work of getting the catalogue ready and distributing it and helping to register people, you know, on the Sunday.

So that got me started in women's stuff. A few months later, probably that would be March of '74, I went to International Women's Day. UC Berkeley had a big event and Sue Sygall was sitting there, staffing a table because she and Debby Kaplan had decided to start having meetings for disabled women--it was called the Disabled Women's Coalition. They had a booth there. Susie was in her chair, and I was on my cane and I walked past her booth, looking at different things and then turned around and walked past her booth again. This went on for about twenty minutes and finally I walked up and said, "I don't know if I'm disabled enough for your group, but [laughter] could I get information?" Susie laughed and said, "Fine, just show up. There's all this stuff happening."

So I started going to her things because she and Debby were sharing a dorm room up at--Debby was at Boalt Law School at the time, or maybe Debby was at Berkeley, I'm not sure, but I think that the dorm room was at Boalt. They were having these evenings and like fifty women were showing up on a Sunday afternoon to just talk about disability stuff. I thought it was cool, but I was also kind of bored with the structure of like just sitting around with fifty women and then not really talking--someone kind of lecturing you and then you left.

Meanwhile, one of the women who had come into Breakaway, to the women's group, was a woman who had been in a really bad car accident, with a limp. She had been riding on the back of a motorcycle and they had been hit on the side with a station

wagon and so her leg had been crushed and so she was in a full leg cast. So I said to her, "Hey, you know, why don't we just do a women's rap group about disability?" Every other class at Breakaway was a women's rap group. She said, "That sounds great." So we advertised that we would do this rap group and we announced it at Susie's group. So by September of '74, I had started this disabled women's rap group. It was Lynn Witt and me with Kitty Cone, Ainsley Tedrow, this woman, Donna, who had MS, who was married with a kid, and Susan Shapiro and I don't remember who else--Kitty might remember who else. We met every week for two years.

We used to meet in the old office--the Disabled Students' Program office--for the most part. And I always remember the week [laughs] that Kitty brought Mary Lou [Breslin]. Mary Lou had come to town. She had just left her sweetie in wherever--Phoenix or wherever--and had come up to see Kitty. She was in a push chair and I remember because she couldn't get up the ramp in the push chair at the Disabled Students' Program. She came once, freaked out, and never came back. And that would happen more than once, with disabled people going, "Ahhh! Disabled people!" when they saw other disabled people.

But it was wonderful. Kitty was like our ringleader. You never had to worry about a topic because Kitty would always come up pissed about something: Do you know what's happening with the buses? Do you know what's happening with my doctor? Do you know what's happening with--[laughter] And she got us all started. So every week we had something to talk about because of Kitty. It was great.

It was a very wonderful experience. It was the first time I had the experience of going from being isolated about my disability and thinking everything that had happened was my responsibility and/or my fault, to realizing that what had happened to me was actually part of a systemic model of what was happening to all of us. It didn't matter whether Susan Shapiro had a broken back or if Kitty had muscular dystrophy or I had polio or Lynn had just had a broken leg; basically what was happening to us was happening to all of us pretty much at the same time.

We sort of came to a systems analysis of it. What was interesting for me--well, two things came out of that. One was that I got very angry. I got like in touch with all of the years that I had not been able to talk about or deal with all of the oppression around my disability. And for about two years there I was like hell on wheels. Susan Shapiro used to say, "We're not sending you on a speaking engagement," because

it was the women's movement and there were a lot of feminists who were really wanting to bring disability into their classes. They taught workshops or whatever, so they would invite us to come and speak. [laughter] Susan used to say, "Enough! Enough. Stop yelling at these people." And I'm like, "I can't help it!" She goes, "Okay, okay, don't go on these gigs for a while." [laughter] I'd just look at their able bodied and want to say, "Do you know what able bodied people have done to me in my life?" It was like, boom! I was off the charts.

It was a very critical time. I could never have gotten--I would never have--it was a step I had to go through. It was painful more for other people than it was for me, but it was definitely a step I had to go through.

Jacobson: How old were you?

O'Toole: I always do my math starting with '51. Okay. [laughter] Well, I graduated college at twenty-two. I was always one of those kids that graduated high school at eighteen, graduated college at twenty-two, because my birthday's in August so I'm always right on track with everything. So if that was '74, I would have been twenty-three years old.

And the other thing that happened out of that group that was critical was that the group was like the camp experience of being with disabled people, except you could really talk about it. Because when I went to camp, even though the director was disabled, all of the counselors were always able bodied, so there was a whole level of dialogue that never happened because none of the adults were disabled. But this group was different. We were breaking the silence, we were talking to each other about what was really happening--about partners, about lovers, about friends, about, you know, social stigma--we were just talking about it all.

But the other thing that happened is PDSP at that point--the Disabled Students' Program--was right on Durant Avenue, so it was like two doors away from Leopold's and two doors away from a little crêpe shop, and so we used to eat out a lot. Before or after the meeting we'd go out for coffee. So it was the first time in my life I had the experience of being with disabled people where like three of us were in a restaurant together. And so, the door would open and they would hear the motor of Kitty's power chair or they would see us clunking along and they would go, "[gasp]." The whole restaurant would stop and stare at us and we would come tromping in the door and I loved it. It was like so [Pavel?]-you know, one person by yourself is like a side show, but like the three of us, we're

the circus! "Hey, you know, you want to stare? Stare at us all!"

And it was so--you know, because I wasn't embarrassed by my friends, so why should I be embarrassed by myself if they're staring at me. I thought my friends were cool, so that was a very liberating experience being in public with cripples and breaking that idea that I could pass. I mean, that really challenged the thing about if you just sit still long enough, you can pass and nobody will really know. And that just got busted really big time.

So that was really the beginning of a lot of that. That got me in the community--through Kitty. Kitty would come and say, I'm working at CIL (when it was still an apartment) and there are jobs. She was sort of--she was our link into the disability community because Susan Shapiro had come to go to college. I don't know where the hell Ainsley--Ainsley was somebody's attendant. She was able bodied. She was a fat woman and she talked a lot about the similarities of oppression. Lynn was a lesbian separatist and was hanging out in the lesbian amazon separatist community and living with people who were part of the Brick Hut Collective, the lesbian restaurant. So basically nobody but Kitty was part of the community--part of the disability community. Kitty was our bridge in. Kitty brought us all--over time, brought every damn [laughs] one of us into the movement. She just hung on to us and guilt-tripped us and loved us and just didn't let us go until we were all in the movement! [laughter]

Pulled into the Movement

Jacobson: How did she pull you in?

O'Toole: Actually she got Lynn a job first. Lynn was friends with Kitty--was actually more friends with Kitty than I was. I mean, we did group together but Lynn would go over to her house and have dinner and stuff. There was an attendant referral job at CIL and Lynn was looking for work and she--she must have been out of her cast by then--and Lynn was pretty anal. I mean, Lynn is really, really good with paperwork and really, really good with money and really, really good with all that kind of stuff. And I don't know whether she started out as helping Kitty do the job--you know, Lynn would do the paperwork part of the job, or it was Lynn's job alone. But CIL had moved, they had gotten big money and they moved down to

Telegraph and Dwight and so there was a job opening, so Lynn worked there like eight hours a week or ten hours a week or something.

But we were also going to group together and then a little while later another job opened up in attendant referral, actually, and they got me a job. I don't know whether Lynn left or--I don't remember working there with them, but they got me a job. So I started--I was still walking with a cane at that point, and I walked into CIL. The funny thing was that when I first came to Berkeley and didn't know anybody in the disability movement, I would walk down Telegraph Ave. and whenever I'd see somebody come by in a power chair--with four surgeries and all this stuff about my legs--I would literally cross the street. I was terrified they were going to hit me. I was convinced that the idea of a power chair on a sidewalk, and certainly people with less than full functioning driving this damn thing--[laughter] because in those days, you know, you had to be pretty crippled to get one--but I thought they were going to hit me! And all those years of surgery and all those years of walking and all that would be forgotten. Little did I know I was going to end up in a chair myself, but at that time I hadn't spent my whole life doing exercises just so some damn cripple could knock me over. So I would just cross the street. I was just bound and determined to stay away from those people!

So then, of course, Kitty shows up at group in a power chair and I get used to her. Then I go to CIL and every other person's a quad, so it was kind of a--it was the beginning of a good education, but I like to remember how phobic I was--what an impact seeing people in power chairs really made. They were very much part of the Berkeley scene even when I first came here. You know, they really were around--not in the numbers--the joke, of course, was for years, for like probably a decade--certainly from '74 to '84--I could almost--I would be with Lynn or with Kitty and we could pretty much tell you, Oh, that's So-and-so's van, or there goes So-and-so. We knew everybody in town.

You know, finally about the mid-eighties, the community started to explode in so many directions that that was no longer possible. You might know that they were with somebody that you knew, but you no longer knew all the dirt on everybody. But in the old days, you really did know. So few people had vans, it was pretty obvious whose van was whose. And you pretty much knew everybody by sight--certainly in chairs.

Jacobson: And you worked at the attendant referral department?

O'Toole: Yes, with Wally Whelan and Phil Chavez. I was the only good set of hands in the department. [laughs] I loved working with them; they were great. Wally was a great education for me because he was really open about being a quad and he was really--he was a guy that had a whole life and was in the community and was running around having a good time and so it was good for me. He taught me about the basics--about what a quad needs, or what on your body works and what doesn't work and how do you know this stuff, and he was somebody that was wonderful that way for me.

Yes, it was a gang. You know, Dale Dahl showed up not long after I showed up at CIL, you know, signing his hemiplegic signing. I knew ABCs from kids at my camp, Maureen Fitzgerald knew some ABCs and there were one or two other people and he just started teaching us to sign. He didn't orally speak--Dale--nor did he speak English, so he didn't finger spell; he only signed. And he was deaf deaf [i.e., he was monolingual in sign language--not bilingual, because he didn't know any English, either signed or written English] so he started teaching us signs. And that was how--up until that point CIL had no deaf services. They had a blind services component and they had certainly wheelchair related services--in those days there was even--I don't remember whether there was transportation right when I started, but there would have been really soon because there was no way to get around town, so they ran a van service.

Jacobson: You became very fluent in sign?

O'Toole: Yes, it took a long time, but by the middle eighties I was fluent. But it was a slow--I signed with Dale a little and he brought some deafies around, but I didn't really sign--I felt like I had it when in '80 I ran a disabled women's project and I hired deaf people as employees. By then I felt like I had my sign locked down--so early eighties. So it was a four-year learning process.

Jacobson: I think this is a good place to stop.

O'Toole: Okay.

Free-flowing Environment

[Interview 2: September 8, 1998] ##

Jacobson: I wanted to ask you about working at CIL.

O'Toole: Okay.

Jacobson: You started out in attendant referral and I'm assuming that CIL was still on University.

O'Toole: No, when I started at CIL, it had already moved to Telegraph-- 2539 Telegraph.

Jacobson: That was in '74?

O'Toole: Yes, '74, '75, somewhere in there.

Jacobson: Okay, so what was it like?

O'Toole: Oh, that's a wild question. [laughter] What was CIL like? [pause] It was a cross between a party, a job-training program, and an office. It was sort of like all three at once. It was always unclear--everybody was a client of the agency. I mean, we didn't have that concept of clients. Everybody used--almost everybody that worked there was using the services of the agency in one way or another and the nondisabled people that worked there were people intimately connected to the community. The same people you worked with or the same people that came in for services were people that you partied with and that you hung out with and that you were friends with.

So it was a very free-flowing environment, which I think allowed a lot of things to happen. First of all, it allowed a lot of disabled people that had never thought that they were ever going to be able to work to come into an agency where other people that looked like them in terms of disability types were working. It allowed people to come and hang around. There was like a lot of that kind of social hanging around so that people got to see what it meant to be in a work environment. And it allowed people to help out and try out and learn some basic skills--because for those of us that grew up disabled, there was no McDonald's, there were no entry level jobs for most of the people--certainly the people in chairs that came up to CIL. This was the first time they ever saw people in wheelchairs working and so it was a really good experience for people to have.

There were a lot of levels, a lot of ways in. It wasn't like you had to go from client to staff--it was everybody was sort of everybody. In those days there was no public transportation. BART was not accessible and the buses were not accessible, so CIL also ran a transportation service. It ran a van repair shop and a wheelchair repair shop, so lots of people in the community got to know each other by using those basic services for people that used chairs.

Blind folks came into blind services. That was the only place in town that had a free braille-writer and material in braille and information about how to get books on tape. It was the information central for the blind folks in town.

So the combination of the services for people in wheelchairs and the services for the blind meant that it was really like a community center, like the way some senior centers function now--the good ones, where people are really involved. There would be classes on independent living skills, classes on basic sign language, but they were informal classes taught by your friends, more or less. They were on a certain day and time, but it was more like hanging out and talking with your friends.

There were parties--every holiday was a party. We were all young in those days, [laughs] so nobody thought too hard about dying. Nowadays, I'm going to more funerals than parties some years, but in those days you were just going to parties. People got to be outrageous. I think that's the thing that was wonderful for me about being there. I had always been really closeted about my disability because it was not an okay thing to be disabled, and here I was hanging out with a bunch of people like quads who couldn't hide their disability, couldn't pass, and we were just getting crazy.

What I'm remembering a lot was the Halloween parties, particularly, where the wheelchair repair guys hooked up a power chair to be operated by remote control and they put a stuffed animal in it and it started driving around the party. [laughter] Or Dale Dahl, who was at that point dating Maureen Fitzgerald. Maureen worked at the Berkeley Women's Health Collective and Dale showed up with a speculum, a surgical mask, latex gloves, and a surgical gown, and then went around to all the women and said, Oh, you want a free exam? [laughter] It was just outrageous. I mean, it was very funny and very silly and very wonderful--just people with disabilities being really off the wall crazy and changing the world. There was very much a sense in the early days that there was a mission, that there was nobody else that was going to do it.

Center for Independent Living: Support for Life Changes

O'Toole: I don't know how we ever got funded. I think a lot about Shelley [Sheldon] Berrol, a doctor who was at that time the head of physical medicine at Santa Clara Valley Medical Center, which was the northern California regional trauma center for the feds--the federal government--and he vouched for us. He would go in with his doctor's suit and he would tell people, "I know that you're not used to talking to people that look like this or talk like this (meaning people with pretty significant physical disabilities), but these people are okay. And what they're doing is really important." He would say it was a necessary component to what he was doing, which was that he could save people's lives and he could get them physically functioning, but he couldn't give them a life. That's what CIL could do--reintegrate traumatically injured people back into communities.

When I think about us--I mean all we did was hang out in T-shirts and blue jeans. You know, the consumption of legal and illegal substances was really rather high in that community at that time; it was party central. In a traditional funding sense, we were not fundable by anybody's stretch of the imagination. Yet, the work that we were doing was really important work and making a difference. We helped people make the transition from no access and no independent life--living with their parents, or living in an institution, living in a nursing home--to believing that they could make the transition to having their own life, defining their own destiny and then actually helping them to accomplish that. It was not the agency that did that, but it was the act of having a central place for information and the resources and community that did that. People could just essentially show up at our door, which they did rather frequently, [laughs] and sometimes too frequently, and we would help them. The whole community would pull together to help each other, so there was a real sense that we were in it together.

Whether it was fighting to get the laws changed--different people at CIL took on different tasks, you know. Greg took on the task of a lot of the legislative fighting.

Jacobson: Greg.

O'Toole: Yes, I can't remember his last name.

Jacobson: Sanders?

O'Toole: Yes, Greg Sanders. He was really into legislative change, so he would, for instance, look up the laws and figure out that the reason that a lot of people couldn't get off welfare or couldn't go to work was because of the work disincentive regulations in various state and federal laws. So he would go to Sacramento, figure out what the vulnerable points were, and then get us all to show up at a demonstration.

Or Hale Zukas was really into the transportation system, so he would figure out where the vulnerable points were in bus access, for example, or in train access, or in getting BART to put elevators in their system.

So different people--and the women took on--I mean, I was really interested in women's issues and I took on some of the issues about trying to get women birth control information and trying to get access to basic services like Planned Parenthood. So different people had different interests and then people basically followed those interests.

What could happen in those days was that you could get the rest of the community to come with you. You could just say, "We need to go bug this person," and you could put up a fire and twenty-five people--disabled people--which in those days was a lot of disabled people since most of these agencies had never seen one--would show up and harass them. We could sit there and say, "Well, okay, where's your Braille material?" Then, "Where's your sign language interpreter, and where's your wheelchair accessibility?" [laughs] You know? They would go nuts.

So it was, I would say, pre-504, pre-'77, so '74, '75, '76, there was a real sense that we were doing something that had never been done before, that we were very deeply in it together, that we had to survive--that there was no other model. There was really no place else for us to go in terms of doing this work, and we needed to--we were in a struggle essentially for our survival. A number of people that had come to CIL, especially spinal cord injury people--quads--had already been in nursing homes. Some of the old polios had also been in nursing homes as kids or spent their whole childhood in hospital-schools. And there was a real feeling that they knew what would happen if we didn't succeed, if we didn't create alternatives--that disabled people were just going to end up in nursing homes, or that the people that could pass and survive, would pass and survive in isolation. The people that couldn't pass and survive were not going to get accessible housing, were not going to get transportation, were not going to get any access to the community. They were going to do just what they

did before--live in isolation, live in their parents' house, depend on other people to get them in and out of a building, out of a home, and not be able to work or have a sex life--not be able to do anything.

And that was actually the other thing about the Berkeley revolution is that very few people ever were from here. Almost nobody was from here. I mean, Ed Roberts was born and raised in Berkeley [San Mateo--ed.] and Hale grew up in Berkeley and Michael Williams grew up in Berkeley, but I almost think of anybody else.

Jacobson: How about Phil Draper?

O'Toole: I don't know where he's from. It was much more typical, particularly for the spinal cord injury people, to be from someplace else. Partially because of the nature of that disability--it's not like it's going to be local. Some of the blind folks were local folks but overall I would say that really for the most part the disabled people came from someplace else. Some people came just because Berkeley was the place to come to. Some people, like me, came totally by accident, for a completely unrelated reason--not related to the movement. Then as it got more famous--like a few people came out here, then they would go back and tell their friends and so there was this whole New York contingent and there was a whole southern California contingent.

There were onslaughts of folks that happened over time, but in the beginning it was mostly people who--Berkeley at that time had a ton of people from out of the area. It was very common for me to meet other Boston and New York people all the time in the disabled community. It was very common for people not to be local people, so it also gave people a sense of, I have to make it here, because I know where I came from and where I came from it wasn't accessible. Over time, a number of those people went back to their home communities and started stuff there, too, but in the beginning days, no.

CIL's Non-Administration

Jacobson: Do have you have any recollections about the administration?

O'Toole: The CIL administration?

Jacobson: Yes.

O'Toole: [laughter] Yes, I can remember a few things about the CIL administration, starting with what administration? The last person who got to Ed Roberts before he signed the check got the decision. It was kind of quasi community consensus, meaning that whenever everybody sort of agreed on something then that's what sort of happened.

We were very crisis-driven, so to a large extent administration was about keeping everybody on board, keeping everybody happy. There were lots of different personalities, lots of different factions, lots of different interests. When I think back, I bet I could trace thirty separate organizations that emerged out of those early days of CIL. There were a lot of people that came to CIL who were not really interested necessarily in a community-based independent living center, but were interested in some aspect of independence related to disability--or parents of disabled kids--but there was nothing, so they came through that door.

So for a lot of people it was like a portal. Then as people got resources, got networks, and got information, they emerged on the other side of that portal. Jackie Brand is a good example of that, or Megan Kirshbaum, or a lot of other people. When they emerged on the other side, they went off in the direction where they started from but now with a whole new set of ideas and community and perspectives.

But in the early days it was very much crisis-to-crisis--like who do we need to demonstrate against right now or whatever. There was also a real funding crisis. First of all, one of the things that was nice was most of the crips--I wasn't one of them--but a lot of the disabled people were on benefits and were receiving some form of social security, social security disability, Medi-Cal, or some variation thereof. So a lot of people had money enough. In those days rents were low enough that if you got a couple of crips together you could get an apartment and afford to live comfortably.

I'm trying to remember whether or not there was attendant care money in those days. I know people had attendants and I don't think only the rich had attendants, so I think that there was some way of getting attendant care money. Because I was working with quads and I don't remember money being that much of an issue.

So you could basically have a work force that you didn't have to pay--[laughs]--so that is what the point of that was--to a larger extent, which meant that you were just basically paying overhead. Rent, and then you know keeping things

running: keeping the vans running, keeping the rent paid, keeping the lights on, and then paying the nondisabled people, and then paying those disabled people that you had to pay. So it was kind of a multilevel thing administratively.

When I first started, Ed was running it by himself. Then not too long after I came on board Judy [Heumann] came on board. And you know, it was still the original guys. Larry Biscamp had left, he didn't want an organization, he didn't want an agency; he kind of wanted like an apartment, a hangout place, a community information center. He had been one of the founders and he was gone by the time--he was around the community and he and Elaine Belkind were partners and he was around socially, but he was not around administratively. And Greg Sanders did legislative analysis type of work and tried to keep the place going. Ed was around, mostly doing fundraising. Joan Leon worked with Ed to make sure that there was money and she did most of the grunt work around finding the money.

Creative Accounting

O'Toole: The rest of it was that you ran your own department and decided what the needs were and just tried to figure out--we had some little piddles of money for attendant referral, housing referral, blind services, and they just figured out how to keep it going. The famous stories are that they, how shall I say it, creatively accounted. [laughter] It was not uncommon for them to get money from X--from a funder--for a van and then get a van donated or use somebody's van and then take that money and pay the light bill or something.

Ralf Hotchkiss has a great story about how he--I don't know if you have this on tape, but how he got involved in the whole movement--this was a little later--around wheelchair design. He was just this tinkerer, who had been a bicyclist into bicycle building and engineering and then broke his back. So he then took all this bicycle training and started to look at the whole issue of wheelchairs because they were awfully clunky and heavy. In those days they weighed like forty-five pounds--E&J--Everest & Jennings chairs. They were horrible. They had straight up and down--you couldn't camber them [angle the wheels], you couldn't change the wheel positions, you couldn't do anything with them. They were horrible things, very uncomfortable to ride in and very difficult to move and not at all designed for outdoor use. So Ralf took one look at that technology and took his bicycling background and started

tinkering. The first time I met Ralf, he was in a 1965 Everest and Jennings wheelchair; he turned the armrests around and used the lower part of the armrest to lock his knees and the upper part of the armrest as a grab rail so that he could pull himself up into a standing position.

He tells the story of--he started hanging around Berkeley and I think he was dating Debby [Kaplan] by that point, or he had come to Berkeley and he hooked up with some people that were doing political work. Some of the leftie crips were doing political work in Nicaragua and wanted him to go to Nicaragua because there were all these people who were disabled and didn't have any access to wheelchairs. And Nicaraguans were never going to be able to afford to buy U.S. imported wheelchairs and they said to Ralf, "Can you help them solve this problem?" Ralf said [noncommittally] well, yes, yes. So they worked on Ralf for a while just to get him interested in the idea. He finally said, fine, but he didn't have any money. I mean, he was a tinkerer, he didn't have any money.

They went to Ed, who took some money out of some pot that was designed for something else, because there was certainly no funder that said, Let's buy a \$500 round-trip ticket to Nicaragua for some guy to do wheelchair design. [laughs] And that's how Ralf went down to Nicaragua the first time.

Then once he got down there and saw what there was and saw what the need was, he got the idea for doing international wheelchair design and wheelchair building. He worked with the local Nicaraguans to find out what was available, which was cars--there were a lot of dead cars--and how to take old car parts and how to tool--he talked to a lot of people that were really good hand toolers--people who could thread a nut and a bolt by hand and make them screw together. And that's where he started. But he said--I heard him give a speech a while back, actually, I think it was at Ed's memorial service--that the only reason he ever got started was because Ed gave him the money for a plane ticket, which certainly didn't come out of any pockets that funded somebody to go to Nicaragua for wheelchair design. [laughter]

So I mean, administration was extremely creative. Let's just say that. But I think that the priorities were right. I mean, I think that if they needed \$300 to send a bunch of people to Sacramento to charter a bus or to drive the vans or to buy lunches, that's what they did. The idea was that the funders gave us money to exist and that we needed to be the ones that decided what existing looked like. And if it was a demonstration, then that's where we spent the money, and if it

was sending Ralf to Nicaragua, that's where the money was spent, and if it was paying the light bill, then that's where the money was spent. So it was administration by need, rather than administration by administrative design.

Part-Time Jobs

Jacobson: How long did you work in attendant referral?

O'Toole: For a while. [sighs] Sorry, those resumes are long lost. I would say that I probably started at CIL probably late '74, early '75, probably '75, and I never left. I sort of went from one job to another and ended up at DREDF, which was a CIL spin-off. But I was in attendant referral part time until the KIDS project came along. And I'm trying to remember when the KIDS project started. I want to say '79. Does that seem like-- Jackie Brand and I were joking the other day that we're going to have to have Judi Rogers--Judi remembers everything. We're going to have to have Judi check our transcripts to find the dates and make sure we get it right. Yes, I was doing attendant referral part time--it was only a part-time job. Most of the CIL jobs were part-time jobs at that point. I think the van drivers had more of a full-time gig, or the shop guys--it was all men in the shop--had full-time gigs, but the rest of us were part-time people. So at that time I was working in the preschool.

I had a teaching credential from Massachusetts and it was in both early childhood and elementary, and I was working just in a regular private preschool, you know, in somebody's house--family day care they call it--up in somebody's house up in the hills. I'd take the bus up every morning and I'd work there from like nine to twelve and then I'd come down the hill and work at CIL in the afternoon. And I did that for two or three years. I did day care from the time a bunch of kids were two until they graduated to go to kindergarten at five, so I was with a little gang of kids. It was a job I really loved. It was a really wonderful job and a wonderful place to be.

This woman named Heidi Hartmann was a German immigrant who had a master's degree in Germany but the U.S. doesn't recognize any foreign degrees at all so in order for her to teach, she would have had to go back to school and do it all over again. I couldn't believe it. That just seems very stupid to me. Anyway, she married an American guy and had a couple of kids. After her first son was born, she started a preschool. By the

time she was getting ready for the second kid or knowing that she was going to have a second kid she hired me because she knew that she needed help in the preschool. And so I came in the mornings and I loved it. I made friends there that I still have.

So I did that in the morning. The maids and I would go up to the hills in the morning [laughs] and work for the rich people in the hills and then we come down the hills and then I would go work at CIL in the afternoon.

Jacobson: How did someone get the idea for the KIDS Project?

O'Toole: There were two parts. We're sort of skipping the whole 504 thing, for the moment.

Jacobson: Well, we should go back then, because that happened first.

O'Toole: Yes, that happened in '77 and KIDS didn't happen until '79.

III SECTION 504 OF THE REHABILITATION ACT OF 1973

The History

Jacobson: So let's talk about 504.

O'Toole: Okay. Part of what happened by early '76, which was an election year, is that CIL had become strong enough that we had a pretty good grasp of the state and local political scene. Greg and Hale really had their finger on where the legislative pressure points were and how to work them and what needed to happen. They sort of in their minds had a fifty-year plan about what was going--what were the legislative changes that needed to happen, kind of in what order at the state level that were going to make a difference. It was clear to both of them that nothing could happen at the state level if the feds didn't change, because too much of disabled people's money and power was tied to the federal government.

Meanwhile on the East Coast, there was a whole bunch of East Coast people starting to work pretty heavily on federal change. In 1973, Section 504 [of the Rehabilitation Act] was written not with a sense of a ground swell of community, but really by some people that saw that the pendulum was going to swing away from giving us rights to limiting our rights and then maybe even taking them away. So people wanted to make sure the disabled people got something in that pot. They were like legislators, legislative aids, parent activists, and some community activists, but I would say quite honestly, it was legislation that was given to us, not really legislation that we really fought for or earned.

Judy Heumann was a big part of that community of people who were on top of the federal legislation, or on top of the federal--how the U.S. Congress could make disabled people's lives easier or harder. She personally had been impacted by

administrative policy type things and knew how that could make your life really miserable.

She came to Berkeley. She was there by '77, so I don't know whether she came in '75 or '76. Ed really recruited her hard. She didn't want to give up New York City, she didn't want to move away from her parents, she didn't want to give up the East Coast power base, she didn't want to give up D.C., she didn't want to give it all up. Ed just really, really, worked on her and basically let her write her own job description--which sort of never deviated in Judy's entire history that I've known her; it's always been basically, here's a job, Judy, do it for me--[laughs] certainly within the movement.

She really wanted to stay legislatively on top of the federal stuff, so when she came out to California, she also started to get Greg and Hale interested in what was happening federally and started getting the federal people interested in the idea of community and independent living centers. I think that the--what was it called in those days--ACCD? No, that's the new one. What was the old one called?

Jacobson: DIA?

O'Toole: No, it was like a National Association of Disabled People--and CPD--National Coalition of People with Disabilities--

Jacobson: ACCD, American--

O'Toole: Okay, American Coalition of Citizens with Disabilities or something, yes.

Jacobson: Yes.

O'Toole: Yes, the blind judge was running it. [laughter] I met him once, I forget his name--some blind guy from the South that was a judge.

Anyway, so she started to make links that really hadn't been made. And CIL was strong enough that we had some amount of clout, or felt like we had some amount of clout on a local level. She started to educate people about the law 504. She started to get people involved in voter registration drives and trying to understand the power--why the legislative process and the voting process was important for people with disabilities to start to make their vote felt. There was enough work done in coalitions around the country, through mostly ACCD, which is the organization everybody was using at that point to talk to each other.

Then they got Jimmy Carter to actually go and make a campaign promise at Warm Springs, Georgia--you know, the site of FDR's first--the kind of the independent living center that FDR set up, actually. Originally that's what it was, although, when I talk to people who went there in the fifties, they said, no, it was mostly professionally--you know, medically--run by then, but he set it up to basically be a cripple-run place. I was reading Hugh Gallagher's book about him, about FDR, and he was talking about how FDR set it up so that it was a disabled-run place, so that disabled people were in charge and the medical people were sort of for hire, you know?

Anyway, so Carter goes to Warm Springs, Georgia, and says--because by now what had happened--it was 1976, the law had been passed--the Section 504 of the 1973 Rehabilitation Act had been passed in 1973 and it basically just said, You can't--

No Enforced Regulations

O'Toole: So the law just said one sentence. It was like a sentence added in. There was Section 501, 502, 503, and 504. And Section 504 just said you couldn't discriminate against people with disabilities in federally funded programs. So '74 went by and there was no enforcing regulations because nobody knew what they meant, '75 went by and there was no enforcement of regulations, '76 is starting and it's a presidential year and there's no enforcing regulations.

Meanwhile, some of the disabled people had been testing it in the courts and getting wildly different interpretations. For example, our classic simple example of 504 and what did it mean was in buses. The federal government department of transportation gave money to city and county bus systems and then the bus systems provided services to the community, so disabled people argued that it meant that buses had to be accessible because they received federal financial assistance.

And in two different regions of the county, two different people in wheelchairs went to bus stops and tried to board the bus and in both cases the drivers said, Sure, if you can get on the bus by yourself with no help, we'll give you a ride. In both cases the people couldn't do that. Both people went to court.

One judge read 504 and said, "Well, it said that they can't discriminate. They didn't discriminate against you, the bus

driver didn't drive away, the bus driver didn't call you names, the bus driver didn't treat you badly--they treated you nicely, therefore, there was no violation of the law."

In another circuit that judge said, "No, wait a minute. That doesn't make sense. The idea of not discriminating in terms of race or gender can mean something like being nice versus being mean but in the case of physical disability it can't just mean if you can get on the bus. It has to mean something more. There has to be, in some cases, equipment or an affirmative duty required on the part of the bus company to take action. It's not just a passive statement."

Anyway, so we were getting these wildly different case laws, so it wasn't being settled easily. Nobody had the same interpretation about what disability meant and certainly what Section 504 meant in the law. Everybody was waiting for the government to write regulations. The previous president had decided that the Department of Health, Education, and Welfare--because disabled people were sick--then HEW was the appropriate place from which the original regulation should emanate. So HEW was charged with developing regulations.

They had hearings, and they had hearings, and they had hearings. They wrote, and they wrote, and they staffed, and they wrote. Nothing ever happened. They would come out with regulations, the community would say, no; I mean, it just went on and on and on. So one of the campaign promises that the disabled community extracted from Carter was that if he were elected president, and specifically if the disabled community supported him for president, he went to Warm Springs, Georgia, and promised that he would guarantee that he would issue the regulations.

Because the community had been fighting about it for a number of years and we'd finally come to some kind of a compromised decision. It wasn't perfect, and nobody was perfectly happy, but we all figured some regulations were going to be better than no regulations. We figured we could fight it out later, because no other agency in the government, like the Department of Transportation, could issue regulations on 504 because HEW had not issued their regulations.

So this is the background of what's going on. So Carter gets elected in November. He has his inauguration, whatever it is, January 20, now it's '77, and so the disabled community's tapping their toes. He appoints a new secretary of Health, Education, and Welfare, which was Joseph Califano. Joseph Califano comes in and the disabled community says, "Okay, so

when are you going to just sign the paper to issue the regulations?" And Califano says, "Wait, I'm a new guy. I've got to look at this. I've got to investigate this. We've got to look at these regulations, we've got to start all over again."

So the disabled community issued an ultimatum--I believe through ACCD--I'm not the best history person on this stuff. Mary Lou [Breslin] and Judy know this stuff better--and said, "You've got ninety days, until April 4. If you don't have those regulations signed by April 4, well, we're going to be talking." And they laughed at us. We were nothing to them. I mean, we were like an insignificant nothing: we were not the AMA lobby, we were nobody; we didn't exist. We were gnats on the face of the earth--not even gnats, we weren't even up to the level of gnats. [laughter] We were ants that they could just step on.

They had no idea that--there was no concept that there was any reason to think that they could ever, ever have to listen to us for any reason. So ACCD said, "Fine," and issued an ultimatum, which was being ignored. And groups affiliated with ACCD around the country made the decision that they were going to go in to the federal regional offices of HEW, set up a meeting with the federal people in advance on April 4. Because of course the government forgot that we issued this ultimatum, so they allowed us to come into their buildings and have meetings with them. And we weren't going to leave.

So groups of disabled people went into all ten federal regional offices of Health, Education, and Welfare and held sit-ins. In a few cases, some groups decided not to hold sit-ins but just to have meetings with the regional director, but in other cities these people decided to stay--just camp out, sleep over, whatever. Some people lasted a couple of days, some people lasted--I think the longest ahead of us was about four or five days. The people in the Bay Area lasted the whole time.

Takeover of San Francisco's Federal Building

Jacobson: Which was how long?

O'Toole: Well, the regs were signed on the fourth of May. That's the official date, so I don't know if that--so about thirty days, twenty, thirty days.

So we all went in on the fourth of April to meet with the local regional secretary for HEW--local regional administrator. The head office is up on the fourth floor of the United Nations Plaza.

Jacobson: In San Francisco.

O'Toole: In San Francisco, right. The United Nations Plaza in San Francisco. It's a beautiful old federal building. It was a wonderful building later because the FBI had a nightmare dealing with us because there were no like ceilings, there were no air ducts, there were no--I mean, it was an old plaster and mortar building. Within a day or two there were 150 people with disabilities and families with people with disabilities living inside the building.

A whole bunch of things happened very quickly. One is that the regional director went home for the day and essentially never came back, so we took over his offices. We took over his three offices: his office, the secretary's office--I never really knew--I'm not a good person to ask about what happened to him.

I remember things like we had some of the people calling the local McDonald's and saying, "Hi, we have a group of disabled people here, would you like to feed us?" And they were like, "Oh, sure," and sent over food for a couple of days, until they saw the news and realized that this was a demonstration, this was an occupation of a federal building.

Somebody went out and scrounged an old refrigerator box, and taped it to the director's air conditioning machine to create a refrigerator for people that had medications that needed to be refrigerated. The building went into a shut-down mode--the FBI showed up after a few days and shut the building down. They allowed the employees in, but everybody had to come and go--so we couldn't come and go because we wouldn't have been allowed back in.

So there were 150 of us inside the building and we're not able to leave the building, but we could wander within the building. The first week was really when they put the thumbscrews on. They figured, "Oh, this is a group of disabled people, they're going to leave in a couple of days," so they didn't give us any access to the media and didn't allow us to do anything. They thought they'd get rid of us. The media did a blackout on us for a few days. Everybody was in the blackout mode--you know, ignore them, they'll go away, it's no big deal.

What they didn't realize was because of the diversity of people with disabilities, we had lots of communications channels. We were up on the fourth floor and the phones were cut off, so we couldn't call out, people couldn't call in, and people couldn't get information. We just went to the windows because every day the people in the disabled community--there a whole bunch of people that didn't want to live in the building and that wanted to be involved--that came every day. So every day there was a demonstration. It was a beautiful building and there was a giant quarter-acre plaza right in front of the building and every day there was a demonstration outside. There were protesters and there were speeches and there were microphones.

What would happen is we would be on the fourth floor and we would sign the news of what was happening in sign language to the people downstairs. Then an interpreter downstairs would tell the media what was going on up in the building and that's how we avoided the communication blockade of the FBI and the nondisabled people thinking that we couldn't figure out how to survive.

The second big issue that we had was food. We could only carry in so much food and there wasn't a cafeteria in the building or if there was, we didn't have access to it. They figured they would starve us out, which is actually what they did in a couple of other of the cities. One of the people with us was a black man who was part of the Black Panthers and he called up the Panthers and said, "I'm here in this demonstration." So the Panthers turned on the news and saw that we were occupying a federal building, which they thought was really nifty. They thought that anybody that challenged the federal government's domain over their lives and were fighting for self-sufficiency and rights were cool people. And they had one guy in there and so they showed up.

They were running a soup kitchen at that point for their black community in East Oakland and they showed up every single night and brought us dinner, for the entire demonstration they showed up. The FBI was like, "What the hell are you doing?" They answered, "Listen, we're the Panthers. You want to starve these people out, fine, we'll go tell the media that that's what you're doing, and we'll show up with our guns to match your guns and we'll talk about, you know, about who's going to talk to who about the food. Otherwise, just let us feed these people and we won't give you any trouble"--and that's basically what they did.

I think the secret history of the 504 sit-in--that almost nobody talks about it--is that we never, ever would have made it without the Black Panthers. The Black Panthers fed us dinner--and they fed 150 people of which only one was a Panther--every single night for the whole demonstration. We never would have survived without them. There's not even a fantasy that we would have survived without them. They kept us physically alive.

The first week was the toughest. It was funny because I think the feds figured, "Oh, they'll fight, or people will get cranky and get tired of sleeping on the floor, and get tired of sleeping in their sleeping bags and, you know, there are all these disabled people and da-de-da." What they really underestimated was our determination. We were high. We were ecstatic. There were 150 of us: some people were blind and some people were deaf, some people were retarded and there were all these nondisabled people and we were like--a lot of us who were disabled as kids had gone to crippled kids camp--we thought it was camp! [laughter] We didn't care. You know, we survived surgery! We survived hospitals! This was nothing! We had choices here. We could go to that inaccessible bathroom, or that inaccessible bathroom. We could go down the halls by ourselves, we were with our friends, I mean, they were never going to get us out of there!

Then they kept thinking, "Okay, well, there are leaders and we'll just wait for the leaders to screw up."

What they didn't realize was we, as a community, didn't function by leaders. You asked me earlier about CIL's administration--we didn't function that way. We functioned by kind of community consensus: when everybody was kind of ready to move, we moved. If a leader-type person said, I want to go off in this direction, and they could get enough people to go with them, then people followed; and if they didn't, then they said, "Well, that's not an idea whose time is now." But that leadership could come from anybody in the community. Hale could say, "Let's go fight about buses," and if enough people wanted to fight, we all followed Hale. Judy could say, "Let's go fight about 504." If enough people wanted to fight, we followed Judy. And if I said, "Let's go fight Planned Parenthood," people followed me. I mean, it wasn't like there was one leader.

The feds were looking for a model, a traditional power structure model of one leader, preferably a man. What they found instead was a bunch of women--because women were primarily--there were a couple of men, but it was like two men

and six women who were primarily the leaders of the 504 sit-in --just kind of talking to the community and hanging out and helping us all.

We would have meetings where we would make decisions as groups: Okay, the feds are saying this to us, do we want to do this? Or the feds are saying things like, There's a bomb in the building, you have to get out! We're like, "Yes, right, okay, fine." Or, "It's really dangerous for you to be here." "Yes, okay, fine." But they'd tell Judy or Ed, and Judy or Ed would tell us, and we'd all go, "Okay, fine, we're just going to hang out here."

It took about--I'd say ten days. The first ten days were really, really rough. There was almost--the Panthers were feeding us dinner, but we're sleeping on the floor, there were no shower facilities whatsoever. Nothing, nothing was happening, but we were having demonstrations outside, the media was starting to cover us, the local media was starting to cover us and the national media was beginning to get interested because all of the other demonstrations had folded at this point, and we were doing okay.

We were really doing okay. We were laughing, joking, and having fun. I was practicing my sign language, you know. [laughs] I was trying to interpret the news very badly one night. I remember somebody got out a little TV--

By about ten days in we were doing things like walking into employees' offices with people when they showed up for work in the morning. And when people called in for information on whatever department--I forget what all the different HEW departments were in that regional office--we picked up the phone when it rang and would say, "Hello, 504 sit-in," before handing the phone over to the employees. So we were impacting a lot of aspects of the building and the business. So cutting off the phones hadn't worked. Cutting off communication with the outside world hadn't worked. Denying us access to bathing and stuff hadn't worked. The disabled people knew they were going to be in for the long haul, and had brought plenty of medications and stuff. We were using the air conditioner to create a little fridge and we set up a little first aid station, so basically people were doing okay. We were camped out and we were in for the long haul. We realized about five days in that they couldn't beat us.

Also, each time another city folded, each time somebody else got thrown out or starved out or convinced out of their city's 504 demonstration, we got more determined that we

weren't going to give in. And about ten days in, the tide started to turn.

A Great Media Story

O'Toole: About ten days in, the media realized that this was a great story. [laughter] We were basically breaking the record for a sit-in, there were no guns, so it was not--there was nothing negative. There was like no media downside to this drama. You know, because in the past--at Pine Ridge or wherever, there were guns or whatever, so that the whole aspect of what the struggle was about was really ousted by the media point of view by guns and stuff. But we didn't have any guns. I mean, we had wheelchairs, you know. [laughter] We were glad to have the wheelchairs and we had survived.

There was a public aspect to it that was going on outside all the time. The political community in San Francisco and Berkeley saw it and started to realize--it's kind of like one of those underground things where you'll have a demonstration and the media doesn't pick it up but your friends tell you about it. Well, pretty soon the underground press in the Bay Area started to carry it, and so we were there a week and then they started to carry it the next week, so more people were showing up every day on the demonstration, covering it outside.

There was more pressure by the FBI to get us out of there, but there was also more pressure from the community to not be mean to us. About ten days into it we started getting things like Phil Burton, who was a U.S. congressman, said, "It seems like this community"--we had had contacts with his office, previously--"the community needs to have a hearing, so I'm going to have an official congressional hearing on the issue of 504 regulations in the federal building in San Francisco in the middle of a demonstration. It's going to be in like a week." Well, that was a big deal.

Then his office said, "Well, if we have a congressional hearing, we can't have a congressional hearing without telephones. We have to have access." So they got AT&T to put in four phones in the halls, because if we weren't going to be allowed to use the federal phones, fine, then they were just going to install telephones.

Then, the next thing you know, [George] Moscone, who was the mayor of San Francisco at that time, shows up and says,

"Oh, this is an emergency housing situation." So they invoke some emergency housing regulations. And the next thing you know, the guy that's the head of the state health department shows up, because the local and state folks are having a blast making the feds look bad, and say, "Oh, it's emergency shelter." They treated it like a Red Cross place and the next thing you know we had blankets, pillows, a little kid's bathtub with a hose that you could hook up to the sink so we could take baths.

The health guy said, "Oh, these guys have to have access to health care providers," which he considered attendants to be health care providers, and suddenly we started getting passes to be able to come and go from the building. People could come and go--say I'm an attendant--and suddenly new people could come in, which was like the feds' worst fear--[laughs] to have these people show up: "Oh, I'm blind, and I'm an attendant," and they come in the building with a backpack and food, not to leave. So the tide started to turn in a pretty dramatic way, which was great for us.

CBS started to show up in this building in the hallways. And while our physical survival went up a minuscule--in terms of we had blankets and beds, mattresses instead of nothing--it was more our emotional support that went up really dramatically because people felt like we were winning. And we were. We had outlasted them and nobody was going to shoot us and all these things were happening.

What became clear politically, however, was that Washington was still ignoring us while we had made a lot of impact. We had succeeded on the state and local level, but we had not at all succeeded on the federal level. And you know, we were in California and who gave a "mmmmnnn" about--who cared about what was happening in San Francisco.

D.C. Delegation

Jacobson: So what changed?

O'Toole: When CBS news showed up, we were like, "Okay, fine," we've got it covered. We've got the discussion going on a national level about what's going on about this issue, but we're not making any impact on Washington. We need to go to Washington. So the decision was made that a delegation of people from the 504 sit-in would actually leave the building and go to Washington. We

got on the phone with a bunch of our union friends and large organizations and started to say, We need help. We need plane tickets, we need transportation, we need housing, whatever.

Then we made a decision about who to send. We sent twenty-two people to Washington. We made a decision about a cross-section of disability, of different racial communities, of age, of whatever, to try to send to Washington. The feeling at that point was that ACCD and other people were doing what they could do politically to make changes, but that what we were willing to do was go on the streets, which a lot of other organizations weren't willing to do. We felt we could be successful in doing the streets' work.

Jacobson: What do you mean?

O'Toole: Well, for example, so we decided to send this group to Washington; we, the group that stayed behind, promised that no matter what, we would stay in the building and keep faith alive until the regs were signed. We were not going to leave until the regs were signed.

And the feds thought, Oh, God, this will be easy. The leaders are leaving and we'll be able to get them all out. Instead, what happened was the group that flew--and I'm not the best person because this is somewhat third hand--but the group that flew to Washington, had housing in a church basement and started doing things like showing up across the street from Carter's church with placards and signs. As he would go in and out of his church, basically saying, "You broke your promise. You promised us you were going to sign 504 and you didn't."

They would set up a meeting with Califano and then when they got there, when Califano realized who he was going to be meeting with, his staff blocked all the federal doors. And some people who shall remain nameless for the moment were very good at this: they would take their power chairs and they would smash into the guards' shins and as the guard was reaching down to say, "You're hurting me," the disabled people would start screaming, "Ah! Oh, you're hurting me! Oh, abuse, abuse, abuse!" So it became--and once you're in D.C., you have the D.C. press coverage of it. Suddenly it was clear to the people in D.C. that all these disabled people were really willing to go to the wall--were willing to hold vigils, were willing to show up at Carter's church, were willing to go to the federal building--to bother the government people around 504. It wasn't an issue that was going to stay confined to San Francisco and that it was going to be happening.

In the end, the group, with the efforts--the more legislative, the more conservative efforts--combined to coerce a meeting at the White House. The joke was--Kitty Cone went to the White House--they get to the White House and Kitty says she has to go pee. Of course the only accessible bathroom was in the presidential wing because of FDR. [laughs] There were no accessible toilets because it's the government--they don't have access. So they made the demonstrators promise to leave the White House if they let them come into the White House to have a meeting. They had to promise not to stay [laughs] and camp out in the White House.

Basically from that end, the government realized that at this point it would be a fierce victory to keep the fight going and that we had won the sentiments of the press, however, whether we were right or whether we were wrong. We had won, and the disabled community was all in agreement that the previous regulations from the previous administration were livable and that Califano had to sign them. So finally, on May 4, Carter just said to Califano, "I don't give a damn. Sign the regs and then get this thing over with."

Most of the demonstrators, though not all, came back from Washington. While we were here in San Francisco, the week or ten days that they were gone to D.C., the feds, every day and every night, were up our butts. They'd set off the fire alarms at three in the morning, and say, "You have to leave now." They figured if the leadership leaves, the sheep will disband. We just kind of hung. We said, "No, we're waiting for Judy, we're waiting for Ed, we're waiting for the gang to come back. When they come back, we'll leave, [laughter] and we're not leaving one second before." So we spent a fairly uneventful week, where basically our only job was to hunker down and hold out.

The Panthers kept feeding us, and our friends kept coming outside, and by now we could go a little bit in and out by ourselves, and we had phones, and so we just hunkered down and waited it out.

A Victorious Exodus

O'Toole: Then we had a wonderful, victorious, fabulous exodus--there's actually some footage on that leaving of the building. It was wonderful to get out of that building. The folks from D.C. came back, most of them, and then we left the building. And we

left the building victorious. Nobody was physically injured on either side--not the guards, not the FBI, and not us. No weapons were used. It was all a battle of words and a battle of wills, and it was very successful. Now, I believe--someone had told me this as a historical fact, that we actually hold the record for the longest occupation of federal property, certainly the most nonviolent occupation of federal property, but I believe it's also the longest.

Solid Community

Jacobson: You call that a real success story.

O'Toole: Yes. Yes, I do. It was wonderful.

And the reason I couldn't answer your other question was because it tied to that time. What happened out of the building was that entirely new coalitions--a whole bunch of things happened because of the demonstration.

One thing that happened was the community, as a people that had not really solidified together, started to work together in a much more profound way.

The deaf community became a much more entrenched part of the physical disability community because of that experience because we were all living there together. We had to learn our sign, we had to do stuff. Previously, at CIL some deaf people who came and went from deaf services didn't really interact with the rest of CIL, but suddenly we were a community of people.

There were a number of retarded people who came to the demonstration who were part of the demonstration who really moved into--we moved into their issues and they moved into our issues in terms of physical disability and retarded concerns.

The parents who came to the building and participated in those demonstrations were parents that had been long time activists and became leaders in the parents' community around disability.

And a whole bunch of new disabled people saw it on TV and said, "Oh! That's what I've been missing in my life," and started to show up. I'm thinking here of like Gary and Linda Gill. There were just tons of people that had never--or people

from the Peninsula, or people from San Jose, or people from the North Bay, that had never been part of the community, suddenly came--were part of either the outside demonstrations, or the inside demonstrations.

Also, the nondisabled community got really politicized about disability. Maybe some of them knew individual ones of us: I was doing work in the women's community and they knew me, but they didn't really see the community that I was part of. By watching on TV, by coming to the outside demonstrations, by hanging out, they for the first time really got a sense that this was a bigger issue than just any one person that they might happen to know.

I remember the guy from BAGEL--from the Bay Area Gay and Lesbian teachers association--came and was part of the demonstration because he saw it as a civil rights political issue. There were entire communities that previously existed sort of separately and side by side, and suddenly became one community. People that had never been part of any community suddenly became part of our community, so there was this enormous expansion of who was interested in disability rights issues, who was part of the community. People started to understand what the issues could be, what power could be, how change could really happen.

People who had no sense of what had been happening the previous five years at CIL suddenly going, "Oh, my God, I want that in my community," or, "I want that in my life." I'm thinking about Lucy Milken, who I remember had been part of the 504 sit-in, was never part of the community before that--although she was active in disability issues but in kind of a more polite way. She ended up going off and starting an independent living center in Redwood City or San Mateo or something.

There started to be this connection, a bigger sense, and it was that one demonstration: those thirty days created like a mushroom effect that went on for the next decade really very profoundly. I think one of the things that happened out of 504, or that culminated in 504 and then led to other stuff, was the realization that just having an independent living center in an individual community wasn't enough. You had to have those kinds of services available to more kinds of people on a local level, but also you needed to create new paradigms, new designs for what could be happening.

For example, the CIL went on and got some Vista money to set up a legal aid center. They went after some Department of

Education money to talk about, "Okay, now we had 94-142 for the Education for All Children Act--passed in '73, '74, as well as 504--so if we're going to send these disabled kids to public schools, we better start talking to the public schools about what to expect." That was the KIDS Project. They had a counseling department, they had a counseling center. So okay, we have all these drugs going on in our community, how are we going to deal with it? How are we going to keep people together so they can survive to be the next round of leadership?

We had to start talking about how we were going to make room for new leaders. To some extent there was this explosion outward of all these new projects and all these new ideas. It was due partially because there were a lot of new people, partially because there were people that were really interested in things other than attendant referral, housing referral, and transportation, and partially because we needed to start creating new leadership opportunities for people.

Jacobson: Is that how you ended up at Antioch?

O'Toole: No, Antioch's a whole different story, actually. Do you want me to continue on KIDS, or go off to Antioch?

Jacobson: Whatever you want.

O'Toole: Let me continue on with this because I think they relate, they tie in.

IV CENTER FOR INDEPENDENT LIVING'S GROWTH OF COMMUNITY PROGRAMS

KIDS Project

Jacobson: We were talking about the tying in of KIDS Project to 504.

O'Toole: Yes, one of the things that happened was that it was clear that a bunch of us working at CIL had other interests. I mean, we didn't want--we weren't housing people, weren't attendant people, but that was our door in at CIL. And as Judy and Ed would go around looking for money, they would talk to us about, "Well, what do you really want to do?" And I'd say, "I really want to either do something in education or something with women. See the kind of money you can find."

So at one point Judy came back and said, "Oh, I've got something on education, do you want to do it?" I said, "Oh, sure." It was a project that Jackie Brand worked on, Judi Rogers worked on briefly, Nancy Thomas worked on that was called--we ended up calling it the KIDS Project--Keys to Introducing Disability in the Schools. It was a project where we did two units--two visits on each disability, on each category of disability: physical disability, sensory disability, hearing disabilities, vision disabilities, and some invisible disabilities, where we would go in the first time and talk to the kids about the disabilities. If it was a disability that had equipment related to it, like braille charts or a braille writer or whatever, we'd bring the equipment and talk to them.

We would leave the materials in the classroom, give them a week to play with the materials, and let the teachers integrate the materials into the classroom curriculum. And then the subsequent week we would come back with a person with that disability that they could then talk to.

So for example, on the blind unit the kids would have looked at the braille dots, played with braille, done braille on paper, written with the braille writer, practiced going around with blindfolds and canes and all that stuff. Then the following week, someone who was a visually disabled adult would come into the classroom and sit and talk to the kids and answer their questions about having a visual disability. So by giving the kids some hands-on experience, and some time to play at the disability, often they had much more interesting questions and ideas about how to think about the disability.

It was a project that I started and stayed with for about two years. And Jackie was there for about two years. Judi left fairly soon after because she was pregnant. And Nancy Thomas was there for a long time. I went off to do some work with DREDF, but the project continued for many, many years. Elaine Belkind kept the project alive, for, God, a good ten years. And a lot of people in the disabled community were a part of that project.

Jacobson: Were you the project director?

O'Toole: No, Judy offered me the director job and I turned it down because I wanted to do curriculum and I didn't want to do budgets. A woman named Lynne Fingerman was the director for a little while but she was not part of the community and she left the community pretty--you know, it was a job. She was new to the area and it was just a job. She came and went pretty quickly from the work.

But Nancy Thomas stayed with the disabled community for a long time and Judi and Jackie are still doing stuff, so it was pretty much a community-based project. It was nice to have Nancy there because Nancy has a psychiatric disability and so she brought a whole understanding to the project that hadn't existed before. She brought an understanding, really, about people with invisible disabilities and about people with highly stigmatized disabilities. Nancy helped us understand why we needed to talk to kids about people with learning disabilities, people with psychiatric disabilities, people with disabilities you couldn't see and didn't really have equipment related to them but had really impacted their lives.

The Antioch College Dilemma

O'Toole: So to go back to your Antioch question. A bunch of things were happening in terms of the CIL explosion and one of those things was having the feeling that for a lot of us community-based people, many of us didn't have degrees, or certainly didn't have degrees in anything that looked like disability. The idea or the feeling was that there was an interest or a need to document and recognize the work we were doing. So Ed and Judy hooked up with the people at Antioch College.

Antioch, which is based, I think, in Yellow Springs, Ohio, had a satellite campus in San Francisco at that point. The director of the kind of community education part of the health [doc. depart.?] was a wonderful old anarchist who really understood--like he liked teaching these kind of classes to labor unions. He really understood how health and communities and disability really interacted, so he was very interested in getting something started. And Antioch was interested in paying for it, so we told them we wouldn't come--nobody would schlep to San Francisco because there was no accessible transportation, or it was barely accessible transportation at that point--so that they had to come to us. So they set up a trailer out in the CIL parking lot, and set up some classes.

The first round was a really interesting struggle because what in reality there was not yet a distinction between people who had a lot of information and knowledge with people who didn't know the information. The dilemma that they had with us as learners (because I was part of the program) was that our friends were teaching the classes and our friends were a little ahead of us, but not so far ahead of us that they were really teaching. It was a big struggle actually. I'm thinking here of when Judi Rogers tried to teach a class on OT stuff which--she knew occupational therapy, but you know, I knew half of what she knew but not the other half. The whole setup was like that.

Hal Kirshbaum came in and taught a class on psychology issues and knew a bunch of--what do I want to say? There was not yet any disability studies, there was not yet a coherent analysis in any discipline--academic discipline--about how disability plugged into it, so we were in the process of essentially making it up as we went along. People like Hal, who had gone to graduate school and had a Ph.D., were trying to teach us material based on how it would be taught in a traditional Ph.D. or master's program. But the material was

not necessarily related to how we were going to learn it or how it really interacted with our community work.

The person that I think was the most successful teacher in that arena was actually Shelley Berrol because he had taught a whole range of classes--he taught medical students all the time. He was a doctor and he was able to--I never forgot this--he was so deep, he--I thought he was so brave to sit with a group of people with disabilities and teach physiology of disability. And I don't remember who it was, but somebody--I want to say it was Mariana Ruybalid but I don't think she was around then--somebody with CP said to him, "What do you think about bracing people with CP?" And he just asked, "Well, is that what they did to you?" And she said, "Yes." And he said, "Did it work?" And she said, "No, and I want to know why I had to put up with it."

And I just remember him saying, "Yes, you know they try it, but bracing eventually never works with people with CP because they eventually break through the braces and it's not an effective intervention. And at that time when you were a kid that's all we knew how to do." It was this very good mixture of physiology--I actually learned physiology from him--but also with an understanding that the people he was talking to had lived through a lot of the theory. It was a very different experience of teaching people for whom the theory was real than teaching people for whom the theory was just theory.

And Carla Thornton and Sue Knight came over to teach a class on sex and disability because they had been running this program in San Francisco [at the University of California, San Francisco], this year-long program of sex and disability training. Carla really was invested in teaching it as a master's degree class and, you know, we wanted to do stuff--like Cece Weeks and Jack Rowan went out and interviewed a series of quads about their masturbation techniques, for example. Carla told them, "You have to do a literature search on it." And Jack and Cece are like, "There is no literature in this field." [laughs]

That's the dilemma we were in. We couldn't do traditional work because all you would do was go to the library and find out that nothing existed. And it was a real tension. Antioch wasn't happy with the program and we weren't happy with the program and eventually they made it into a program where they brought in nondisabled teachers to kind of teach traditional classes about--and then made it a counseling, you know, like developing therapists program.

The class that finally made me quit the school was the class where they brought in this very nice woman who was a nondisabled therapist and she was teaching a class on child development. Oh, god, what is her name? Bonnie Regina--the woman who always wears the rainbow clothes--she's got spina bifida and has no bladder control, never had bladder control. So the teacher was teaching theories of child development and is talking about critical milestones in toddler development, and is talking about continence, bladder continence, as a critical milestone. And she goes through theory A, in Adler and Freud and Erickson and Piaget, and all this stuff.

So Bonnie raises her hand and says, "Okay, so, you know, how can we think about these theories and how can we accommodate these theories in relation to people that never achieve bladder continence?" And the teacher's comment was, "Well, according to these theorists, then emotional maturity would never be achieved, number one, and number two," her comment was, "and I've never thought of that before." And my feeling at that point was, "Why am I sitting here with you? Because that's exactly the thing I want to be thinking about."

I'm not saying that someone had the answer, but I wanted teachers that could say, These are the theorists, this is the experience of disability, and how can we marry the two? How can we create new paradigms? What does bladder continence mean in terms of emotional development? You're not going to write off an entire group of people because they don't have bladder continence. I understand that it's not the majority experience, but it certainly is a disability experience, so that was the point at which school no longer seemed quite as relevant to me.

But those were questions that I was fascinated by and I'm glad now that--it took another twenty years--I'm glad now that there are people in the world of disability studies that are thinking about those questions and are interested in those questions because those were the questions that fascinated me.

A Home Location for Thriving Interests

Jacobson: Corbett, how were you personally affected by CIL?

O'Toole: Well, in a whole bunch of different ways. I think that what started with the disabled women's rap group, which was hanging out with a group of women and talking about the experience of

being disabled and having a similarity of experience, got me started. I think that CIL gave me kind of a more professional location for my interests.

I just wanted to go back and talk about the disabled women's group. It was all white. Kitty had muscular dystrophy and used a power chair. Susan Shapiro was spinal cord injured and used a push chair. I was walking with a cane because I had polio. Lynn Witt, who had been in a car accident and had her right leg smashed pretty badly, was in a leg cast for most of the year and used crutches. Ainsley Tedrow didn't have a disability and was a large woman, and Donna, whose name I don't remember, had multiple sclerosis, and actually used her dog to kind of help her walk, especially up and down stairs.

That group gave me a grounding and an understanding of how the personal is political, to use kind of seventies feminist terms, but it didn't give me a sense of how to make social change, except that people who stick together can make change. What CIL did was gave me a home. I mean, for the first time in my life, I really felt like I was home when I would hang out at CIL. I felt like all of the parts of me could be present: that I could be a woman, that I could be disabled, that I could be, you know, interested in education, that I could be present in a whole bunch of ways.

I came out as a lesbian in 1974, late '74, and CIL was a place where there were a lot of lesbians. There were a couple of gay men, there weren't very many gay men, but there were a lot of lesbians and so it was place that I just felt pretty safe in. Even the straight men were not particularly homophobic because we were--like I said, we were all in it together. Although there were lots of things that could have divided us about age or race or income or whatever, we just chose to be in it together and see each other as mutually helpful. So that was one thing it gave me--it gave me a sense of home.

It also gave me a lot of information, I mean, stuff that was not available in books. I didn't know anything about spinal cord injuries before I started working there. I didn't know anything about muscular dystrophy, I didn't know anything about deaf people. I didn't know anything about blind people. I had gone to camp with disabled kids, but that's really different than hanging out with people and dealing with leg bags, or braille, or sign language, or going with them to the grocery store and the coffee shop. It was hanging out with people where you really got to experience in a much more direct way what their lives were really like and how they managed.

How did people who were quads physically manage in the kitchen, how did they manage in the bathroom? How do you manage attendants? What's the role of an attendant, how do you balance that? How do you have a sex life? What kind of sex do you have? How do you find partners, how do you communicate about it? How do you have kids? I mean, all of that stuff--because somebody at CIL was doing all of it. Judi Rogers was having babies, Janice--oh, God, I am so bad with names today.

Jacobson: Krones.

O'Toole: Yes, Janice Krones had already had a couple of kids. Certainly closer to the beginning of the eighties there was a whole disabled baby boom [disabled people having children], but in the seventies that wasn't as true. Certainly people were having lots of sex--I mean, there was lots and lots of sex going around.

And Kitty was having sex and I'm like, "Well, if she can have sex, I can have sex." [laughs] There was a lot of feeling that there was a lot of information and there was a lot of living life--of just being out there, of people being--

You know, Sue Sygall had started BORP by this point--Bay Area Outreach Recreation Program, which used to be called the Berkeley Outreach Recreation Program. You could go skiing with BORP and she had classes, she had weekend trips, she had day trips, so lots of different people with disabilities and their families and their friends could go do social, physical things together.

So there was a feeling that anything was possible because the jocks were all being jocks, and the eggheads were off being eggheads at school, and the teachers were off teaching, and the parents were off parenting, and everybody was crippled. So there was a feeling that--and certainly in the deaf community it was very common for them to be parents, so that was not even really a question.

So it was very educational. You got a lot of both the popular ideas of what people could do, but you also got the negative ways that society tried to stop people from making choices--how they tried to not give birth control information to people with certain disabilities or tried to take their kids away. You kind of got the whole spectrum.

And the feeling was that if we just stick together and fight it out we can make changes. I also realized that I was very interested in teaching, but not necessarily in classroom

teaching. That was certainly what my credential was in, but that really wasn't what I really wanted to do, sit in a classroom and teach kids. I liked being in the community, I liked talking about issues, I liked teaching that stuff. I was a really good networker, and those were things I learned at CIL. Those were things that certainly in the old days of CIL were very valuable skills to have.

You know, people could say to me, Corbett, I need X, and I could find a person that matched their needs. Or, I need information about short-statured people who got pregnant, and I could find somebody with that information. So it helped me in a very real world way take my kind of interests, which didn't really fit in any academic arena, and refine them to where I sort of knew what I wanted to do and knew what my work was and had value. So I left CIL.

By the time I left CIL to go to DREDF, I felt like I had value as a person, I felt like I had value as a leader, because I had been validated as a person because--because all parts of me could be present at CIL. I had had lots of opportunities to do leadership activities, to plan events, to figure things out, to write, I had done a lot of training, particularly within the nondisabled women's community around disabled women's issues with other disabled women. I had also, after the rap group, kept the disabled women's coalition alive and ran it as an office out of UC Berkeley for a number of years. I was able to work. I worked as a teacher and really liked it, but really liked the disability rights work a lot more. I had a career. I had both a personal interest in disability but I also had a professional interest in disability and decided that that's where I kind of belonged. And by the time I left CIL, I felt all of those things.

The reality of my life, now twenty years later, is that many of the people I was friends with in CIL in the old days are the people I'm still friends with. It became a base that's essentially lifelong, even though, as I said, a lot of us went off in lots of different directions professionally. Because we came through the same door and because we see all the work as intrinsically tied together, it doesn't matter whether people are doing computers or parenting or school work or whatever, it's all the same root, we're all kind of branches off of the same tree.

Branching Out to the Disability Rights Education and Defense Fund

Jacobson: One more question.

O'Toole: Okay.

Jacobson: You went on to DREDF to do work with disabled women. How did you end up focusing on that?

O'Toole: Specifically on disabled women as role models?

Jacobson: Yes.

O'Toole: Oh, God, that's a hard, complicated question. Well, I started with DREDF in not running their women's project. I started with DREDF because CIL/DREDF got a grant from I don't know where--the Department of Justice, I think--to go around and do trainings for disabled people in the communities--parents and disabled people--on what their rights were under 504, so that's how I started with that organization.

While they were writing that grant, they were looking around to the federal government for other monies and they found the women's educational equity act fund. At that point, they were giving three-year grants--fairly large grants, like \$100,000 a year to do work on women's issues, women's and girl's issues in schools--and they applied for the money and got the money to do a women's project and asked me to run it. When I sat down to look at the project--you know, the parameters were not that tight: you know, kind of do something about disabled women and girls that would be useful in schools --there were a lot of challenges.

The challenges were, number one, that we didn't know anything about disabled women and girls because nobody had collected material, so I decided that we needed to do a national survey on disabled women and girls and get that started. The second challenge was, if we're going to do something, we should have a way to talk about it and disseminate it to the professional community. So we decided that for year two we would do a conference for educators and policy-makers about what we know about disabled women and girls. And we would do the No More Stares book as part of that project so we would have something to show them about how we see our own community and also something to give to the schools. Because of the work on the KIDS Project I wanted to have something that we could put in an elementary school classroom.

The third thing we decided to do was to do work directly with young women--to say, "There are lots of opportunities in the world. You don't have to be limited by the choices that you've been given. We're a whole community: we may not be so visible in the town you live in, but there are opportunities there." So it was the multi-level, multi-strategy project.

Do you want me to go into the years now, or do you want to do it next time?

Jacobson: Let's stop here.

O'Toole: Okay.

V AN EXPLORATION OF DISABILITY ISSUES

[Interview 3: September 18, 1998] ##

Initial Interest in Women's Issues

Jacobson: Corbett, let's get into your involvement in women and disability issues--and I first want to ask, how did you get involved in women's issues?

O'Toole: I don't know that I can--I can tell you the chronology of what I did, but I don't know that I know how I got involved. I think that growing up in a traditional American family in the fifties, I saw the impact of sexism. There were four girls in the family and the girls all did chores and didn't get paid, but my brother took out the trash once a week and he got an allowance for it, you know, because my father said that was like real work. But the fact that we were doing the dishes every night wasn't real work. [laughter] So inequality was never something that went over too well with me in any regards, but I didn't really do too much about it.

I wasn't involved in women's stuff in college. Well, I went to a very small college and there wasn't really any real women's stuff happening there.

But when I got to California, and I had time and didn't know anybody, and one of the first things I found was at that point there were a lot of rap groups--which had a totally different meaning in the seventies than it does in the nineties. [laughter] In the seventies it meant discussion groups. Women got together who didn't know each other and just talked about different aspects of their lives and tried to understand what their connections were, and what was societal oppression versus what was individual differences in family and personality and stuff.

Then I got involved in Breakaway, which was a group of women would get together a couple of times a year and connect with women who wanted to teach classes. The teachers would come on one session--an announcement was posted in the local women's press and in the local bookstores saying, "If you want to teach a class to women, come on this Sunday night, let's say, in January." The women who wanted to teach a class would come that night and write a description of the class. Then they would all go away and then the people in the collective would compile them all and print a little newspaper and then they would distribute that little newspaper to the community. And then on, let's say, a Sunday night, the first week in March, the women who wanted to take classes would show up and sign up for the different classes and get the information about where the classes were held and pay their money.

I thought that was a nice easy group. And they always needed an extra set of hands, so I just kind of hung out with them for a couple of years and through that got hooked up with the local women's community--got a lot of information about local women's resources. It was a group of women across ages, across sexual orientation, across race, so it was a nice way to get started in the Bay Area.

Through that and through the disabled women's coalition that Sue Sygall and Debby Kaplan had started--I decided that even though I liked their meetings--they were having these big meetings where fifty people showed up and kind of had a lecture. I really wanted to do something more personal and so I started a disabled women's rap group that used to meet at the old disabled students' program at UC Berkeley on like Sunday afternoons. So that got my foot in the door about women in disability issues.

And then the women's movement people--some of the people I knew through Breakaway--other women who were active in women's political issues, or that women in the group knew--were teaching classes at universities, were doing other kinds of work, and would say periodically, "We don't get it about disabled women. Can some of you come and talk to us?" So we were going to classes at UC Berkeley that might be on nursing, that might be in sociology, that might be in women's studies, that might be--or the community colleges, or like there was very active women in therapy collective organization.

Jacobson: Now, what was it that they didn't get?

O'Toole: Is, Everything, too simplistic an answer? [laughs] They grew up in the same time frame that I grew up in. None of us had

really had the experience of having disabled and nondisabled people physically in the same schools or in the same neighborhoods in a way that was where there was equality. I mean, there might have been disabled kids in the neighborhood, but they probably didn't go to your school or they weren't your friends, they weren't part of a social circle of peers. So by the time people got to Berkeley--because a lot of people moved here from other places--they had no experience with disability.

Just like white women were talking to women of color about race issues--"Can you talk to us about what we don't get about it?"--it was pretty much the same thing about disability. They didn't have any familiarity, they couldn't figure out how to think about disability, but we as disabled women were turning up in the community. They were seeing us in the grocery store; they were seeing us in the streets; if they were in the nursing program, they were seeing us as patients in their health practices; if they were therapists or mental health practitioners, they were seeing us as clients. We were starting to appear and we were on the edge of their world and they figured out that they needed to talk to us about it.

Mostly they had no exposure to disability. They had no place to discuss it and nobody to discuss it with. They needed us to connect the dots for them between disability, oppression and sexism and how the oppressions related to each other. They wanted to know what kinds of situations and contradictions did they create for women with disabilities. They needed us to give them really basic access information: how do I serve a woman--someone calls me and she's in a wheelchair and I don't know what to do, I don't even know the questions to ask--. They had questions about language--so it was kind of a full spectrum of information.

I would say at that point with very few exceptions, there was nobody that really wanted a lot of depth. Mostly people wanted us to come and say, "You know, disabled women exist and disabled girls exist and we need the services that you are providing to women. And if you are saying that you are a women's shelter, or you're a women's health group, or you're a women's rape crisis line, these are the issues where we as disabled women and deaf women cannot access your services. We're asking you to start to get some more consciousness about that."

Sexuality and Table Manners

O'Toole: I would say the singular exception to the lack of interest was actually Cheri Pies who at that point was a health educator at Planned Parenthood in Oakland. She got really interested in disability issues and did a lot of work to make the connections with disabled women, with the disabled women's community, to make sure that disabled women started to get included in the purview of who Planned Parenthood should be serving. As part of the work that she did with a number of other women--for instance, the book Table Manners came out of work that was done because of Cheri pushing inside and disabled women pushing outside. That was the result of Planned Parenthood finally getting interested in sort of documenting the disabled women's community and some of the issues--in this case, how to do examinations.

Jacobson: What is Table Manners?

O'Toole: Table Manners is a book that was done by Susan Ferrerya and I forget--Katrina--

Jacobson: Katrine Hughes.

O'Toole: Okay. They were hired by Planned Parenthood to do a book. And by the time they did the book, which was the late seventies, early eighties, there were a number of materials out about disabled women and sexuality. The people in Seattle, the women in Seattle had a contract with a major, family planning provider up there to do some different kinds of research. What, do you want to interrupt me?

Jacobson: What group?

O'Toole: Oh, god, I think they called themselves the Task Force on Disabled Women and Sexuality. I'll have to look up what they were called.

Jacobson: That sounds about right.

O'Toole: And there were four women. Jane Bogle and Susan Shaul were the women that I had the most contact with, but there were four of them and they wrote a series of two small books. One was called Toward Intimacy and the other one was called Within Reach. And one of them, I think this was Toward Intimacy, talked about sexuality issues, but also talked about birth control: what kinds of birth control information did we know at that point for women with disabilities. It included

information on what kinds of sexually transmitted disease issues were relevant for women with disabilities, how do you treat it, how do you give exams, I mean, so it was a basic--but it was all text, so it was pretty basic information.

What we found then, which was very frustrating to me, was that we kept being told, "This is what we know about birth control pills; this is what we know about the side effects of birth control pills. Therefore we're going to guess that maybe they'd be contraindicated for women with these disabilities." But you know, that was fifteen years ago, eighteen years ago, and we still don't have very much better information now.

And the other book, Within Reach, was more like telling family planning providers how to think about access. The gap was that people who were doing hands-on--nurse practitioners, physicians who needed to do GYN exams on women with different kinds of physical disabilities had no hands-on information about how to think about what kind of positions would work, what ideas would be useful. So Table Manners was designed to literally be a guide towards women having a GYN exam, women being on the table, as it were. It included things like, how to get women up to the table. Then there were a lot of simple line drawings, very clear, very explicit, saying, you know, if a woman has difficulty opening her knees, separating her knees, these are the kinds of positions; if a woman has difficulty bending her knees, these are the kinds of positions.

What I jokingly say--well, really with some degree of seriousness--when people say to me, "What should I know about sexual positioning for my disability?" I say, "Well, let's start with Table Manners [laughs] because it will basically show you how to get access to a vagina, and once we figure out how to get access to the vagina, we can go from there, depending on your sexual interest and the behaviors that you like."

But the combination of Toward Intimacy, Within Reach, and Table Manners created this real milestone of information that had really never been available and, in my opinion, really hasn't been duplicated or replaced since, where there's really one-stop shopping about information on disabled women and sexuality. So we were able to do some workshops with health care providers, with people that were dealing with sexuality issues, or people that were interested in talking about sexuality issues.

For instance--I don't even know what they call themselves these days--is it called the National Sex Institute or the Sex

Information--San Francisco Sex Information Switchboard--and the folks in San Francisco had a Ph.D. program in sexuality. And they started bringing disabled speakers in to talk about sexual arousal and behaviors and what people liked and didn't like in terms of sexuality for people that had disabilities, as well as having some people with disabilities going through their programs. The sex information switchboard was good about gathering information and training people to answer the phone about sex information as it related to people with disabilities. This was all pre-AIDS. I'm talking about when AIDS didn't exist and people just were talking about disability in the more traditional categories of physically disabled, blind, deaf, and going from there.

Jacobson: Do you recall what period it covered?

O'Toole: Hm, I am so bad with time. None of this would be later than '82 because my feeling is that by late in 1982, early 1983, which was when I was doing the women's project, my feeling is that the momentum had stopped. The money had dried up, the base of the work had been done.

Jacobson: Yes.

O'Toole: So I would say that most of this work is like very late seventies, at the latest, early, early eighties.

Jacobson: The sex and disability program at UCSF I believe started in '76.

O'Toole: Right, because the teachers from there came to teach at the Antioch program.

Jacobson: Yes. That would have been Susan Knight and--

O'Toole: And Carla Thornton.

Jacobson: And that program got the first three-year grant in '76, and the second three-year grant in '79. Then the money dried up in the Reagan years.

O'Toole: Oh, yes, we all dried up in the Reagan years. [laughter]

Jacobson: That was about '81, '82.

O'Toole: Right. Then their book came out of that experience, kind of closing off that part of the world.

Jacobson: Table Manners?

O'Toole: No, the book that Sue Knight and David Bullard did.

Jacobson: Right.

O'Toole: The book on physical disability and sexuality came out at that time.

Jacobson: Right.

O'Toole: I mean, I think that that sort of closed that chapter--well, in terms of information, certainly. Yes, because there was a lot of stuff happening locally. I mean, I never forgot Cece Weeks and Jack Rowan wanting to do research on how quads masturbate. I thought it was fascinating, and you know, nobody was doing it. Well, Cece--but Cece was unusual because she had come out of that Minnesota Sex and Disability program that, oh, god, Sandra--

Jacobson: Cole.

O'Toole: Cole--Ted Cole and Sandra Cole--were running. She had been one of the quads--she was sixteen years old when they grabbed her right out of rehab. They may have waited until she was eighteen and out of rehab and then trained her to be a sex educator. So she came here with a certain level of sophistication out of that program that was atypical for a lot of local people who were here. There were a lot of quads that had been like in nursing homes and stuff, not given great rehab or sex and disability training. [laughs] So it kind of put a different spin on it.

So for me, in '74, '75, '76, I'm doing a disabled women's group, I'm hanging out and talking to nondisabled women about disability issues, kind of as it comes, you know, different women at different times.

As I said before, from probably '75 and '76, you wouldn't have wanted me to be the speaker in your class. [laughter] I kind of was a little--I was a little too much in touch with oppression and not quite enough in touch with the bigger picture of life, meaning that I was pretty angry. I really understood how nondisabled people oppressed disabled people and how nondisabled people benefited from that oppression, so when I was speaking to all groups of nondisabled people, especially when they were health practitioners, [laughs] I was not exactly the calmest speakers. I recognize that it was a phase that I had to go through, that it was a part of my development as a person, as a speaker, that I just had to deal with. And I did and by '77 I was a lot calmer.

I was still doing women's work then: we were dealing with Planned Parenthood, we were trying to get more work happening. One of my projects for Antioch is I interviewed a bunch of disabled women about their sexuality issues and health care experiences. I still actually have those tapes, by the way. Sue Sygall had left the area and Lynn Witt and I were running the Disabled Women's Coalition office out of UC Berkeley. Lynn Witt and I became lovers in '74, '75, and we were running the disabled women's office and kind of being a coordination central.

I was working at CIL in the afternoons, I was teaching preschool in the mornings, just kind of generally doing stuff. And I did 504, and hooked up with a lot of women in the 504 building that kind of continued afterwards, and then started working on the KIDS project. That didn't have much of a specific women's connection. I was also training the people who became DREDF--the CIL legal department which ultimately became DREDF.

Disability Law Resource Center and the 504 Trainings

Jacobson: Was that DLRC [Disability Law Resource Center]?

O'Toole: Yes, the legal resource center. Yes, it was a Vista [Volunteers in Service to America] project. Vista funded a couple of lawyers to come and work for us and then we put a couple of people into them. It was this nondisabled man named Jim, I want to say Jim Pechen, and a disabled man named Bob Funk, Robert Funk.

And Jim was just there--you know, he was being paid to coordinate the program. He was just there because he liked poverty law work.

Bob, who had been in the Peace Corps, had gotten leprosy in the Peace Corps, and had lost most of one leg to leprosy. Unfortunately, what they did--he was in Africa and they took him out of Africa to do rehab on him, and the people in the states had no clue what was wrong with him. He said the only reason he's alive today is some missionary doctor wandered through his ward and said, "Oh, I see you've got a case of [blah blah]" and then he went, "What?" He had some form of leprosy. And you know, who in Kansas has ever seen that form of leprosy, so they had no clue what they were looking at or what to do and they were just cutting his leg off in inches.

Anyway, Bob was sort of a closet cripple--he wasn't very in touch with his disability stuff. But he started hanging out at CIL and looking around. And he got it--he really saw that this movement needed a legal defense fund, you know, on the model of the NAACP defense fund and that we didn't have it. He hung around a couple of years and realized nobody was going to do it.

Bob was not a very public person and he didn't like the limelight at all. He didn't even like talking to funders. I mean, he would write anything and he would do all the hard work, but he didn't like any of public stuff. So he hooked up with Mary Lou Breslin, who at that time was running an employment program at UC Berkeley--and in a power chair, per our earlier conversation. They started talking about what it would be like if they worked together, because she was good at the schmoozing and the talking nice to people and the public stuff.

Jacobson: You mean that she started out in a power chair?

O'Toole: Mary Lou? No, when I first met her and she moved to Berkeley--I don't know what year it would be--when I was in the disabled women's rap group, which was like '74, '75 to '77, she was in a push chair. She came to one of our meetings in a push chair. I remember that she could hardly get up the ramp and we all looked at her and go, "Why the hell aren't you in a power chair?" And she's like, "Don't talk to me like that!" [laughter] We all knew each other pretty well by then, so she was really kidding. She was an old friend of Kitty's--Kitty Cone. They had gone to college together at the University of Illinois, Champaign-Urbana.

So anyway, she and Bob started talking about what if: what if it was more than just a Vista project, what if there really was a legal support system for people with disabilities, what would it need to be, how would it influence policy, what role would it take? There was a bunch of issues that came up.

One of the things they did involved one of the pushes with getting the 504 regulations implemented. We were fighting with HEW to pass the regs, to sign the regs, to get them in place, but then the next push was to train consumers. There are people all over the country and they have no clue they have these rights, they have no clue what to do. Bob and Mary Lou in California and a number of other people around the country pushed the Department of Justice to put money together to do a series of trainings for, you know, "Know Your Rights," like they had done on Title VI and Title VII.

So Bob and Mary Lou got the contract for, which was then, the legal resource center in CIL to do the trainings. They initially owned the western region, and then ultimately did the West and the Midwest, going around and doing 100-person trainings in each state, in all thirteen western states, on knowing your rights on 504.

Jacobson: Corbett, can you clarify Title VI and VII?

O'Toole: Yes, Title VI and Title VII are the civil rights laws that relate to the kind of thing you see on employment forms: you know, you cannot discriminate against--on the basis of--. Initially, I believe, and I'm not a legal expert, so this is not going to be legally correct, but this is sort of community correct: you can't discriminate on the basis of race, of national origin, of language. Over the years a number of other categories were added to include age and gender. Not sexual orientation, yet. I'm not sure what the whole list is. I believe VI is everything except employment and VII is employment, I think is how it goes, or certainly how it went in the seventies.

Jacobson: VI would be housing?

O'Toole: Yes, and it depends, I don't know what the laws exactly said, but it was sort of that you shall not discriminate in federally funded programs, you shall not discriminate on the basis of race. When we say in casual language "civil rights laws," usually what we're referring to is VI and VII as the touchstones. Now, the lawyers will say to us, we're probably referring to a group now of forty separate laws--probably one for housing, one for transportation, one for government contracts, one for whatever. But in general, when we are casually saying, "civil rights laws," meaning protection against discrimination, we're usually referring to Title VI and Title VII.

Anyway, Bob and Mary Lou got this money and they were talking to Judy [Heumann] and they all decided it was going to be better if there was a legal spin-off, because at that point, by the late seventies, there were starting to be spin-offs. You know, Hal Kirshbaum and Megan Kirshbaum, who had been doing the counseling program, were looking at the need to have a counseling kind of spin-off to serve families and to be in the community. The Antioch program sort of showed us that CIL couldn't be all things for all people. The transportation stuff was spinning off; AC Transit was starting to pick up some of it, they were starting to develop ParaTransit instead of CIL providing private transit.

The guys that were running the van shop wanted it to be a commercial business. The guys that were running the wheelchair shop wanted that to be a commercial business. People like Jackie Brand who worked with me on the KIDS Project wanted to go off and do computer stuff and started the whole Disabled Children's Computer Group, which ultimately became the Alliance for Technology Access. So people were starting to feel like they had enough of a grounding of community that they could start to spin-off and do stuff that interested them and were more particular to their interests. The writers were starting to write, the actors, like Vicki Lewis, were really starting to act--I mean, people were sort of going back to their interest areas. Bob and Mary Lou wanted to do legal stuff, both legal aid for people with disabilities, national policy issues, and then training for people with disabilities.

And so I got hooked up with them and was one of the trainers that worked for them going around the country. I was doing the KIDS Project part of the time and I was doing the 504 training project. The training project involved flying into a town on, let's say, on Thursday; then--we stood in a big conference room and trained 100 people--basically talked at 100 people all day Friday, all day Saturday, all day Sunday. And because my rules of expertise in the trainings were on parent issues, I did all the parent training. I had been a teacher and I had been teaching in schools, and I had done the KIDS Project and so I had some understanding of what was then called 94-142, Public Law 94-142, which became the Education for All Handicapped Act, which is now called IDEAS. So at night I would often do parent groups. We would train during the day and then I would do parent groups in the evening.

Jacobson: How did they get people?

O'Toole: That was not my job, but that was somebody else's job. Basically they hooked up with local coalitions, because you know there were always people--there were always like the handicappers group in Michigan. There were always different groups--the deaf people had always been networked, the blind people had always been networked. The people that were harder to find, actually, were people with physical disabilities and people with invisible disabilities. But the parents were always hooked up to each other, so basically what we were trying to do was identify people that were already networked because then what you wanted to do was train the trainers. You wanted to put information in the hands of advocates, who were working at the state and local levels, so that they in turn would put information in the hands of the people they were seeing. We inundated them with paper--I mean, manuals and

manuals and manuals and, talking and talking and basically going through the manuals and answering questions and then doing the manuals some more. [laughs]

One of the people that got brought in early on in this process was a man named Alan Kalmanoff, who we all called Kal, who was a nondisabled man who was entrusted in this contract, just because he runs a private consulting firm. He just did all different kinds of stuff--he's a lawyer--and he was interested in training. What Bob and Mary Lou realized is that we knew disability issues and we could certainly learn 504 and a bunch of people had been active in terms of understanding the law, fighting for the regs, so we had knowledge. What we didn't know how to do was teach a large group of people. So Kalmanoff came in and for the first year basically babysat us and trained the first group of us as trainers. Then went on the road with us for almost a year showing us first how to do stuff and then showing us how to handle things like the logistics. For instance, what do you do when the microphone's not there, who do you have to talk to in a hotel, what do you do about food, I mean, showing us how to do logistics and then training a logistics coordinator for the road.

We were traveling with usually three trainers, one or two attendants--we brought our own attendants because most communities didn't have attendant care--two to three interpreters, sign language interpreters, and then a logistics person, so there was a group of however many that is--seven or eight people. And [they] went on every road show, because we'd go to communities--it was like no wheelchair accessible transportation. We had to tell people, "If you come, we will get you out of bed, we will get you up in your chair, we will help you eat your lunch, we will provide sign language interpreters, we will have braille, we will have tape." You had to do that or else people couldn't function. Because there had been no rights, because there had been no access, there was no availability of those kinds of service at a community level on a consistent basis.

You could go to one town like Denver that might have it and you'd go to Salt Lake City where they wouldn't. I mean, we trained in Pocatello, Idaho. We were in Boise, Montana. You know, we were--we also went to Honolulu twice. [laughs] That was the plum trip. That was the trip everybody fought for was the Honolulu trip. But I mean, you had to bring your own--you had to bring the support services because people didn't have them.

Advocate For Serving People with Developmental Disabilities at CIL ##

O'Toole: Okay, so we were talking about DREDF and we were talking about the 504 trainings and I was talking about working with a lot of parents who had disabled kids.

I think that the 504 trainings for me really made a lot of changes in my life. One is that, you know, I had grown up without any sense of a disability community, so coming to Berkeley and getting hooked up with the disability community was really major. But I mostly ended up knowing a bunch of, you know, transplanted East Coast people, [laughs] who were white, who were primarily physically disabled, primarily people with spinal cord injuries, who were a lot of the people I knew who worked at CIL. And then I was doing a bunch of the women's work. But it was a somewhat insular community, especially in those days when, you know, you basically could ride down the street and know every van in town and pretty much know every cripple in town and go, "Oh, well, that's So-and-so."

After 1977, Berkeley started to explode after the demonstration because new people started coming into CIL. People also started to splinter off. You know, some of the people that had been at CIL started to think about where they really wanted to be professionally; they didn't really want to be information referral specialists for independent living, they wanted to do counseling or computers or whatever, so that explosion was starting to happen.

Jacobson: If I remember, didn't you start a mentoring program at that time? Isn't that when you hooked up with Jennifer [Luna Bregante]?

O'Toole: No, that was actually a whole different story. That was in 1979. CIL was pretty big at that point. And two women showed up one day at CIL's door: Susan and Maureen Walsh. And Maureen had been mostly in retarded classes; she was very high functioning. Susan had been mostly in classes for kids with emotional disabilities. And as young adults, as like eighteen year olds, they had ended up in the same kind of work training program. They realized that they were friends and they realized that they didn't want to--that if other people could live on their own, that they wanted to live on their own.

So they started taking off--they were both from Marin County--they would take off and end up here or there and somebody would find them. Or if they got hungry they went to

the local hospital, someone would call their parents, and they would get sent home. So eventually they heard about CIL.

And [laughs] this actually happened many different times. I mean, we would literally get calls from the San Francisco airport police saying, "We have this person. They're in a wheelchair. They say they're coming to CIL. Could you please come get them." This was like Friday afternoon, they'd flown in from New York, and we didn't know who they were! They just thought CIL had housing and all this stuff and that if they physically just got themselves on the plane, we would figure out how to take care of them. And usually they were right and usually something happened.

But anyway, Susan and Maureen were both ambulatory--were both not physically disabled. And they showed up at CIL and CIL freaked out, basically. They freaked out for a number of different reasons. They freaked out because at that point there was not much happening with services for people with either developmental disabilities or people with mental health illnesses. Also they freaked out because they were young--they were like eighteen. We were more typically seeing people in their young twenties, we were more typically seeing people with college educations and not kids running away from sheltered workshops. People were freaking out because of their perception that they were lesbians because they were best friends and they were presenting themselves as best friends, and basically CIL did not want to provide them services.

I happened to be at work that day when they came in and realized that they were basically getting stonewalled and were going to be thrown back out on the streets. So I sort of sat with a number of people--the woman who did the youth program, Sandy Stone, the people that did housing referral, the people that did benefits, and said to them, "These are our clients, just like the quad that just rolled in is our client. We have to serve these women." And I basically kind of handheld the service providers until we all agreed that (a) they had to call home and tell their families that they were safe and alive, but (b) they did not have to go home. They were adults and we were not in any way going to force them to leave the facility and we were going to assist them.

There really was no other service in the community at that time that really was designed to provide independent living skills for people with those kinds of disabilities, so I probably took them home for the weekend--I forget how we first housed them temporarily. But they both had social security money, so we had that money transferred into their own name, we

helped them find an apartment very close to CIL and, for a number of months, they came to CIL every day for independent living skills help. At some point in this time, I'm not sure when, CIL actually had an independent living skills class and they started to attend that. We found a woman in the community who was working with people like them, developmentally disabled adults who were trying to make it on their own, trying to stay out of the clutches of board and care homes and sheltered workshops.

Jacobson: You remember her name?

O'Toole: No, I'm trying to remember what it was.

Jacobson: Marsha--

O'Toole: Golden? No, Marsha--I may have it written down somewhere.

Jacobson: Ann Cupolo might remember.

O'Toole: Okay. Marsha was really good at helping developmentally disabled adults make choices and empowering them to make choices because her feeling was that's what nobody ever did-- wait for them to decide what they wanted to do.

I was terrible with a checkbook, and still am, so I brought Lynn Witt in to help them balance money because she was very good at that. She was still around Berkeley. She was, in fact, working for Mary Lou at that time. She was Mary Lou's assistant and so Lynn came in and started working with them with checkbooks. We put them on a budget: on Mondays they could go to the bank and take out \$40--because there were no ATMs in those days--and they could go grocery shopping, and then on Fridays they could do the same thing: go to the bank and take out \$40. And that's all they could do. If they wanted spending money, then they had to work a formula out with Lynn for spending money. And so that's how they had their food and their spending money and that's how they lived for a whole bunch of years. In fact, eventually SSI caught them and said, "You have too much money," [laughs] because they hadn't spent down enough.

So over a period of about five or six months they became pretty independent and I just saw them socially, you know, occasionally and--"Hi, how are you doing and you want to go for coffee," and whatever. They fit in perfectly well with the Telegraph Ave. crowd, they were able to kind of roam the university campus, they liked movies, they liked magazines, they had a life.

But Lynn was getting pretty concerned about the fact that their behavior socially--private behavior, not public behavior --but socially and sexually was pretty different. For instance, they would buy teen and movie star magazines and they would cut out different movie stars from different television shows and they would hold their pictures up and they would have the pictures kissing each other. And sometimes it was two girls and sometimes it was a girl and a boy and sometimes it was two boys.

Lynn thought we needed some intervention. So I started asking around for someone that could handle sexuality information, developmental disabilities--basically with adolescent issues (I felt like it was not atypical adolescent issue)--and that wouldn't freak out that they might be lesbians, because we didn't really know what was going on. And it was none of our business, it was their private life. And it took me a while to get a referral to Jennifer Luna Bregante, who at that point was running a facility in San Francisco called the Green House which was part of youth advocates, which was a facility that was working with teenagers at risk. Jennifer's facility took the kids that had bombed out of pretty much all of the other placements and a number of whom who had a lot of sexuality issues. They were either kids that had been put in foster homes where they were repeatedly sexually abused, where they were cross-dressing kids, or they were gender disoriented children, as they would say in the system.

It took me three weeks of calling her every single day before I got a return call and actually hooked up with her. She agreed to meet with the adults--not Maureen and Susan, but with the other adults that were working with them--which was Lynn, this other woman, Dale, and me to talk about what were our concerns and what were our issues and how did we want to proceed. So we met with Jennifer and talked to her about what we had seen and how these women had become very independent but this was an area where we thought they might need some advice and would she be willing to advise them.

She did a series of consultations with them and talked to them about how they were doing and about their behavior. Basically, Jennifer said that they were fine and we should get out of their business and leave them alone. Their behaviors were satisfying their sexual needs, and it wasn't harming us. They weren't acting out in any negative way in terms of public behavior and everybody has a different way of--you know, different strokes--. And leave them alone and get out of their bedroom--and so we did. [laughter] So that was actually how I

met Jenny, who was my partner for many years, actually--from about 1980 to 1997.

Pervasive Discrimination

O'Toole: During this time I was on the road a lot with 504 and I really learned a lot from being on the road. I really saw how absolutely pervasive disability discrimination issues were, and how totally common. It almost didn't matter what town I was in, it almost didn't matter what state I was in; people did not have access to public transportation, parents were slugging it out with individual school districts over really stupid silly things like an accessible bathroom for their kid, employment was--forget it. Nobody had jobs and nobody could get jobs. Independent living centers were just beginning to be glimmers of ideas in people's minds and they were trying to fight for them.

And at the same time, there were these incredibly strong coalitions of people all around the country. When we trained in New Mexico--it was interesting because New Mexico refused to accept 94-142 and so there was no right to an education for handicapped children in the state of New Mexico because they didn't take the federal funds. And yet the parents--they were totally organized, totally fighting, and totally using 504 to get what they needed for their kids in the schools. What I saw was that the community was alive and well way outside of Berkeley. There was a lot of resilience and there was an amazing cross section: some people wanted to be bureaucrats, some people wanted to be activists, some people wanted to be, you know, in the trenches, some people wanted to have demonstrations. I mean, there was a whole spectrum of how people wanted to fight, but everybody wanted to fight back because there was massive resistance to societal oppression about disability.

Schisms within the Movement

O'Toole: At that same time, the movement was overwhelmingly white, and overwhelmingly populated by people with either physical disabilities or blind or deaf. Mostly those groups didn't talk to each other particularly well. People who had other invisible disabilities were totally outside the spectrum of the

movement. Any issues that related to divisions or discussions were completely obliterated. You did not have discussions about how deaf culture related to physical disability culture, or discussions about what it means when the physical disability movement is run by white people and how that impacts the fact that we're not serving people of color. You didn't have the voices of people of color. You didn't have voices of women, parents didn't talk to people with disabilities, and people with disabilities didn't talk to parents. I mean, I saw like a lot of schisms that I thought were harmful to the movement.

Jacobson: Did you see a hierarchy among disabled people?

O'Toole: Oh, yes, the hierarchy sort of depended on what community you were in. You know, if you were in the deaf community, it was the people who were signers and had high status in the deaf community that were at the top of that totem pole. People who depended on oralism were at the bottom of the deaf totem pole, but then if you went into the hard of hearing world or the hearing world, they were at the top of the deaf. You know, so for instance if an independent living center had to talk to a deaf person, they wanted to talk to an oral deaf person who could read their lips and not need any interpreters and not need any sign language, so the hierarchies would switch.

Jacobson: What about in physical--

O'Toole: Oh, in physical disability, white men in wheelchairs--well, white men who could walk who were visibly disabled but who could walk were actually at the top of the totem pole because they had the disability stigma, but they could go anywhere they wanted to go. And they were usually the ones that sort of traditionally within the male disability culture were the most desired males, so they got the most girls of the heterosexual males. They got the most girls so that was the most desirable. If you had to be a disabled man, you wanted to be a physically disabled white man who could walk.

The next level down was paraplegics, in the men's community. Then there were quads and then there were people with other kinds of disabilities. If you had walking CP you were below the quads with speech involvement. If you were in a chair with CP you were above the people who could walk but had speech involvement, so you know, the hierarchy kind of went down.

If you were more middle class, you were higher up the hierarchy than if you were less middle class in terms of, you know, being able to speak and kind of represent the community,

and represent our perspective looking like a middle class person. I'm thinking here of Gary Gray, who's a black man in a chair but who's missing front teeth. Very often people did not want him to be the representative of the disability community on an issue because he didn't look like a college-educated middle class man, like a white man would look. He looked much more working class and much more black than people were comfortable with.

Men were always higher status than women, so men within each category were higher status with women. I think the categories of physicalness didn't change, it's just that if you had--a para woman was higher status than a quad man, but a quad man was higher status than a quad woman, so I think that that didn't change that much.

I think that the other issue that came up was that in terms of partnering and in terms of sexuality that disabled men had a much easier time finding partners than disabled women. Disabled men were just seen as much more desirable by both disabled women and nondisabled women whereas disabled women were not usually in the category of being that highly prized. I think that on a sexuality scale it totally tipped. You know, much more severely disabled men had much easier access than much less severely disabled women.

Jacobson: Did you see a difference between the acceptance of gay disabled people in the disabled community as opposed to the gay and lesbian community?

O'Toole: I would have to talk about them separately. I would say that gay men reported back to me that being disabled was a distinct disadvantage, particularly in the seventies and early eighties, particularly pre-eighties, when body type was highly prized and disability was really a major taboo. Their experience was that they were very rejected by the gay men's community and that it was very, very difficult for them to get partners. Except for deaf men: I met a whole bunch of deaf men that were very successful at getting partners sexually, particularly if they were willing to be part of the casual sex community. Whereas physically disabled men or blind men were not acceptable either in the casual sex community or in the relationship sex community.

I would say that the situation for disabled women was significantly different. I encountered a lot less discrimination being part of the lesbian community than did my friends who were straight and trying to find men. For a whole bunch of reasons--partially that the women who were lesbians

were already outsiders, that women who were lesbians were much more, I thought, generally accepting of a much wider range of difference in terms of body type, in terms of class history, in terms of difference. As women, many times they'd been caretakers in their families of other members of their families that had disabilities--their grandparents or their parents--so that their hands-on experience with disability was much higher than a comparable man, let's say, from their own families.

I wouldn't say--I mean, it's not perfect--if I'm a physically disabled woman wanting a particular woman, and there's a nondisabled woman who wants her, too, I'm much lower status. But the fact that women were more willing to think of disabled women as partners I found much higher. And I think that that's the same hierarchy. I mean, that women who walked had a much easier time of getting a partner than a woman in a push chair, and a woman in a push chair had a much easier time than a woman in a power chair. And partially it's because housing is almost never accessible so, you know, it's about being able to go to each other's houses, going to each other's parties, going to each other's stuff. The ways that you meet people are much more impaired by social access and private spaces.

But I found the lesbian community a lot more accepting in a surprising way. I mean, I recently, you know, got divorced and I'm using a power chair and I've been surprised by the number of people that have approached me and said, "Hey," you know, "you're available--let's have sex." And I was like, "Me? You know, I'm a large woman, I'm in a power chair, and I have a kid. [laughter] You really sure that you want to think about this?" They're like, "Yes, this would be fun." I'm like, "Okay, whatever." So, I would say that there were differences. I would say that if you attributed me and another woman of my age and who was living in the same basic geographic area for men versus women and we were both dating at the same time, that it was easier for me to find partnership.

Jacobson: Than--

O'Toole: Than a straight woman with a similar disability looking in the same area.

Hierarchy at CIL

Jacobson: Okay. Now, was this going on at CIL, too, this hierarchy?

O'Toole: Yes, CIL was such a funny place in those days. I think that at CIL that there were a number of ways these hierarchies played out. I think class and education had a lot to do with it. I think that if you were at CIL and you had a college education, you were automatically in the higher status category. Regardless of type of disability, you know, you moved up the ladder. You were seen as someone who could be employed, someone who could speak about the movement, someone who could sort of represent the right look of the community. And if you were white and you had either a middle class background or you had a college education that made you look like a middle class person, I think that you had the possibility of status and could move up.

Because CIL was started by, you know, five guys--four white guys in wheelchairs and a white blind guy--white guys in wheelchairs were pretty high status at CIL.

Jacobson: Who was the blind guy?

O'Toole: I want to say Dennis Fantin, but I don't think that's right. We have to think about who's alive who can tell you that story. [laughs] Kitty could tell you that story. Kitty Cone could tell you exactly who the blind guy was, because I'm thinking, you know, it was Greg Sanders and Ed Roberts and Larry Biscamp and I don't know who the fourth guy was, was it Phil Draper? And then I don't know who the blind guy was.

Jacobson: Or Hale?

O'Toole: It might be Hale Zukas. It might be Hale Zukas.

Jacobson: He's not blind.

O'Toole: No, no, I mean, I don't remember whether it was Phil Draper or Hale Zukas who has the fourth wheelchair guy slot. So white guys in wheelchairs and basically people in wheelchairs were very high status at CIL.

In fact, my feeling a lot at the beginning--I was still walking when I started working at CIL and I was walking with a cane and my feeling was I was very low status in the CIL world because I didn't have a chair. You know, I wasn't crippled enough and I didn't look--at least the blind people looked blind when they had the canes and the people with physical disabilities had the wheel chairs, and I just didn't look quite crippled enough. If I sat in a chair and put my cane away, you didn't know I was disabled, whereas people in chairs were disabled all the time. So having a wheelchair was a big plus.

And I think also the deaf stuff was--you know, because of the way that deaf services started--did I tell the story already, that Dale Dahl story, on the tape?

Dale Dahl and Deaf Services

Jacobson: I don't remember.

O'Toole: I was working at CIL, and this guy comes in riding in a power chair. It was Dale Dahl. He had grown up deaf, he had gone to traditional schools for the deaf, he never learned to speak, and he didn't really read and write English; he only spoke ASL, which is not a written language. He showed up on CIL's doorstep one day and he started hanging around. And you couldn't write to him very well because he didn't read and write in English, and nobody there really knew any sign, but there were a couple people there--I knew some ABCs [finger spelling], Maureen Fitzgerald knew some ABCs, and a couple of other people knew, too. We just started hanging out with him.

Jacobson: And he came in a wheelchair?

O'Toole: Yes, he had been born and raised deaf. And I'm not sure what was the cause of his injury--he had a spinal injury. I don't know whether he was in a car accident or whatever. And he was a hemiplegic and so one side of his body was pretty, you know, quady, although he could walk a little but not very well and he had one hand he could sign with very well. I mean, he had horrible stories about being in an accident, being taken into ICU, being put in a halo [head traction] and laying flat on his back for three months with nobody signing to him or telling him what's going on. I mean, his experiences were terrifying.

By the time I met him, he was running an ABC ring, so he had an apartment which he rented for a group and then he had these guys work for him who were lower-functioning deaf--lower functioning in the sense of being able to function in the hearing world--than he was. And he would give them housing and give them beer and give them food and then every day they would go out and sell so many of the alphabet cards--the sign language alphabet cards--around the community and bring the money back to Dale. They would give all the money to Dale and he would pay the bills. That's how they all lived. That's what he was doing when I met him.

So he just started hanging around CIL. And because it was wheelchair accessible and most of the deaf stuff at that time--the deaf culture was all up two flights of stairs. The division between the deaf and the non-deaf world had been so much ingrained for so long. Even though he was a member of the deaf community, he was a lowest status member of the deaf community because he wasn't considered to be an educated member of the deaf community. The educated people could read and write [English] and he couldn't read and write, so he was not a high status person. He was a low status person, so nothing changed when he became in a wheelchair, whereas let's say if the head of the school for the deaf had had that kind of same accident, there probably would have been a change in access within the deaf community. But because it was Dale, there was no change. So he was looking for places to hang out and people to talk to. And he started hanging around CIL.

And his friends started coming by and his ABC card sellers started coming by and pretty soon there was a realization that we needed to serve deaf people. And there was a need--there was no community TTY [teletype machines]. TTYs in those days were very expensive and most people did not have them. Most of the time if you wanted to find a deaf person, what you did was you drove to their house and you went to see if they were home. Dale couldn't do that so he convinced us to get an old TTY from a newspaper and put in a community TTY so the deaf people could actually talk to each other by coming to CIL and actually making phone calls. And we would accept messages for them and put them up on the bulletin boards and stuff.

And he is the only reason that there was deaf services at CIL. This drug-dealing, ABC-pimping, spinal cord-injured deaf guy showed up and wouldn't go away. And you know, that's how I learned how to sign; I learned to sign from him and his drug-dealing friends. And you know Maureen--Maureen and I are the ones I remember. And he started classes and he got his friends to come in and start classes. This is way before Vista [Vista Community College's American Sign Language classes], this is way before.

And then once he got it going and once the middle class deaf community realized that there really was a readiness and a need not only for people to know sign language, but for deaf people to have more interpreters that were community-trained, as opposed to sent away college-trained, then they took it over and it became very middle class, kind of--very sophisticated. And now it's a model program nationally. You know, the ASL language training program is a very intensive two- or three-year interpretive training program.

Jacobson: Can you talk about what Dale Dahl started?

O'Toole: Well, Dale was in 504 and I remember that Joe Quinn and Maureen and Jadine Murello and all the interpreters--and the interpreters didn't come around until there was deaf people, and Dale brought in, you know, Steve McClelland and he brought in Olin Fortney, and I remember that whole crowd of deafies, because there was a big crowd of deafies in the 504 sit-in. So by April of '77 there was a deaf community that was attached to the disability community in a direct way and so he had to have come by around '75, '76. Maureen would know these dates, by the way.

Jacobson: How did CIL get the funding?

O'Toole: Hm--wrong person. No, I remember things like thinking about Dr. Shelley Berrol basically fronting us to a bunch of funders. You know, that he'd--when I think back about it, we were basically this bunch of people that wore blue jeans and T-shirts to work: we had no concept of dressing up, we had no concept of talking to funders, we just knew we were right--and right was on our side and we were going forward.

I can't believe anybody actually funded us. I mean, when I think about the hoops I have to jump through now to be presentable to a funder, especially if you want more than \$500 --if you want like \$20,000. People like Shelley Berrol just stood up and said, you know, [in a deep, mock authoritative/laid-back voice] "I am the president of the California Association of Physiatrists and, you know, I am a doctor. I run the trauma center of Santa Clara Medical Center and these people are what my people need when they get out of my facility." It was amazing. It's just dumbfounding.

And without people like him or Joan Leon who came to the movement with Ed to fundraise for Ed--and she started out as a housewife who was a fundraiser. And I mean, you know, she just wrote letters for Ed because he couldn't write them and then, you know, she figured out how to fundraise. And she stayed with the movement thirty years, you know, to make sure that we got on our feet. And you know, that's the stuff that's really amazing.

Or Edna Brean, you know, who's a nurse who came in to like vouch, "Attendant services don't have to be medical services, we can train community people to provide basic attendant care services. And our mortality rate was significantly less than what the hospital mortality rate or nursing home mortality rate was for providing the same services." So I mean, there were

some pretty outstanding nondisabled people that fronted us to the nondisability community professionally and said, "I'm putting my degree on the line for this community of people because they are doing the right thing." And that made all the difference. I mean, to be able to say to a funder, "We have this doctor and this nurse."

And Hal Kirshbaum had a Ph.D., Megan Kirshbaum had a Ph.D., and we had these people saying we're doing the right thing. You know, it made us look much more legitimate than if you walked into CIL and hung around with us or came to any of our parties, God forbid. You know, [they were] much more respectable than we certainly thought we were and certainly than the world would have seen we were. I mean, lots of times all they saw was Ed and Shelley Berrol and Joan Leon, which was good [laughs] because the rest of us were in the back room, you know, being in our overalls, being wild people, emptying our leg bags in gutters, you know.

Jacobson: That may be a good place to stop.

O'Toole: Fine with me.

DREDF: Origin's in CIL's Disability Law Resource Center

[Interview 4: October 16, 1998] ##

Jacobson: Okay, we were talking about DREDF. Now, do you recollect, did DREDF come out of DLRC?

O'Toole: Well, I would say yes, but I'm not sure technically how correct that is. Bob Funk was working as a VISTA lawyer for DLRC--

Jacobson: And that's the Disabled--

O'Toole: I think it was the Disability Law Resource Center.

Jacobson: Right.

O'Toole: And it was a project of CIL, it was just like housing or just like transportation. It was just like a department and it was a project. It just had its own name because they wanted to have their own phone number in terms of legal referrals and stuff. And Bob saw that CIL wasn't necessarily the best place for long term for a legal agency--Bob Funk--and that there

needed to be a defense fund, which other movements had but which at that point the disability movement did not have.

There was nobody in Washington making that happen, so he started meeting with Mary Lou Breslin, who at that time was an employment counselor for disabled students at UC Berkeley and I think alumni, too, at UC Berkeley. They started talking about what kind of legal services did the disability community need and how should that best be coordinated and what should that look like.

And out of that project came DREDF [Disability Rights Education and Defense Fund]. And I think DREDF may originally have actually been under CIL's, not DLRC's but CIL's 501(c)(3) until it got its own 501(c)(3) because it was bidding on grants--it got the Department of Justice grant to do 504 training when it was still CIL because I remember that you got your paychecks from CIL.

But it was an intentional transition. And in those days there was a lot of that kind of stuff. People were starting to spin off for lots of different reasons. The people that did the counseling program ended up going off and doing the Through the Looking Glass, and the KIDS project eventually spun off into its own nonprofit, and DLRC as DLRC didn't last, but DREDF spun off, and then eventually there were other community-based legal services.

Jacobson: And DREDF physically moved.

O'Toole: Yes, well, when the grant money came in, when the big bucks came in.

Jacobson: Where did it move?

O'Toole: I'm trying to think. I know where it moved to for the big move, but I don't know if there was a smaller move before that. The move I knew about was on San Pablo right near University.

Jacobson: And did it maintain any ties with CIL?

O'Toole: I don't know how to answer that question. I would say that in those days, certainly we're talking 1978, '79, '80 here, in those days we were very much--we all felt like we were part of the same community. You know, the community was still pretty small. You could still drive down the street and know who was in every wheelchair in town and whose van it was. And so they were seen as separate organizations in terms of purpose and

funding but they were seen as sister, if you will, organizations that did a lot of collaboration.

Jacobson: It was run by Bob Funk?

O'Toole: And Mary Lou Breslin.

Jacobson: Who came on board?

O'Toole: Well, from the organizational point of view, it started out with Bob and Mary Lou. Bob was kind of the official executive director, you know, did the paperwork exec stuff and hated the fundraising and the meeting work. I mean, he'd write the grants, but he hated the face-to-face type of work, so Mary Lou did a lot of that kind of talking sheep stuff and managed the day-to-day operations of the organization and did direction stuff.

By October of 1980 they had gotten a women's grant and that's how I became staff for that project as opposed to just a consultant person on the 504 project.

They had a bookkeeper named Jeanne Freidman, they had a couple of lawyers--Kim Swain was one of them. I'm trying to think of who else was there. Shirley Nakao was one of their staff lawyers, Debby Kaplan was an early staff lawyer at DREDF, people like Margaret Jakobson was an intern, at one point--kind of law-clerked there. I'm trying to think of who was regular staff. Who I remember was Jeanne Freidman, because everybody knows the bookkeeper, and Bob, and Mary Lou.

Jacobson: So what did they do?

O'Toole: Well, in the early days in '79 and '80, DREDF had an enormous--a couple of big contracts. The big one was the DOJ [Department of Justice] contract to go around to the thirteen western states and train people in their civil rights.

Jacobson: The Department of--

O'Toole: Justice. And that was an enormous project. That meant every single month all year long, or sometimes twice a month, they had to identify a pool of disabled people and train them in the law. They had to give them training in the technical aspects of the law--they had to give them training in presentation styles, and then they had to actually go and put on three and four-day conferences all over the thirteen western states. The first year they just had the West, but by the second year they

had the contract for both the West and the Midwest. And that continued for a third year.

Then the Department of Justice started identifying that there needed to be regional trainings for higher level leaders. So you know, the first round you'd go into a statewide Utah and train 100 people. And in a state like Utah, 100 people was about as many disabled people as you were going to get in that kind of training. In California that was nothing. You were throwing people away, you were kicking people out the door in order to just only have 100, so they started to have second level trainings--higher level trainings.

But that was an enormous undertaking. And Mary Lou pretty much coordinated that, did all the--you know, selected the people, trained the people, coordinated that. There was a consultant, a nondisabled consultant named Alan Kalmanoff who was involved in the beginning for quite a bit.

Jacobson: We talked about him in the trainings. But DREDF also got into taking legal action. Were you there when that happened?

O'Toole: When they were taking legal cases?

Jacobson: Yes.

O'Toole: I was there. I wasn't that involved in it because the legal department was sort of more of a world unto itself. You know, Bob was trying to--there were a lot of problems because what the community needed was a lot of service. What DREDF was funded for was more like providing technical assistance to legal aid organizations, which in those days weren't around, referring people to individual lawyers, but really not taking too many cases directly, except in selecting a few cases.

You know, I think--I want to just go back for a minute to the 504 trainings, is that okay?

Universal and Personal Effects of 504 Trainings

Jacobson: Yes.

O'Toole: Because what I think was significant about that--I mean, I think it was a real milestone for the community in a couple of different ways. One was that the Bay Area community, because all the trainers were from here, got an enormous wealth of

legal expertise infused into it in a way that never would have happened if it was just Mary Lou, Bob and one other person going on the road and doing all the trainings. But because they saw it as a community leadership project, probably like fifty people by the time they were done actually knew the law well enough to get up in front of a group of people and for three solid days train people, answer questions, and run small groups.

It was a wild cross section of the community--it was people from all disability groups: people with epilepsy, people with cancer, and people who were blind or who were deaf, or who were physically disabled, people with speech disabilities, so that that was one really important critical component. People in Berkeley, who up until then had been somewhat localized and, you know, through the 504 sit-in somewhat regionalized, really for the most part, all grew up in nondisabled worlds. They knew some disabled people, but they certainly didn't see themselves as part of a global movement in any way, shape, or form. In taking on this assembly of people with groups of three and four and five--because, in addition to three or four trainers, we brought along sign language interpreters, a logistics coordinator on the road, attendants, so there was a group of seven of us traveling wherever we went--we were realizing that the issues that you or that your friends were talking about were issues not only here, but in Butte, Montana, and in Hawaii, in New Mexico, and all over the place.

And people were fighting different fights. You know, in those days there was no [Public Law] 94-142 in New Mexico and there was no Title XX money, no money, no attendant care money. In Arizona, they refused that money, so realizing that people were dealing with different situations in terms of the technicalities. And they were organized in different ways: if you went to Michigan you had to use the word "Handicapper" because that's the way--you know, but the basic fundamental issue of disabled people everywhere were working together, fighting against discrimination was I think very profoundly changing.

I think that the 504 trainings for the Bay Area community infused an enormous amount of knowledge about people's civil rights and globalized people's perspective about how pervasive discrimination really was. It did it in a way so that those people really went on in many different ways to just become community leaders on a whole new level in terms of providing community-based information and access.

In most states, at that point, in the late seventies, early eighties, people didn't have much money and there hadn't been much in the way of conferences. I mean, maybe the National Federation of the Blind had a state conference and maybe the physically disabled people had a conference, but they didn't have major coalition conferences. If you did, it was somebody's turf and so there were fights about how all of it was going to play out and the role of parents and all that stuff. But here we came into town, we were the outsiders, we were just hosting a conference where you had to be disabled or a parent of a person with a disability in order to attend and participate in the conference and get the materials. We brought together these enormous cross-sections of people that were not used to working together, were not used to sitting in a room together, were not used to listening to each other's issues. I think that that process--I mean, it was a real movement-building process, even though technically it was just about learning the law. You know, there were a million ways--we could have sent them tapes--this was a very profound way to make--and also we were modeling access.

Jacobson: Yes. It sounds like it had a profound effect on you.

O'Toole: Oh, yes.

Jacobson: And can you talk about that?

O'Toole: Okay, well, for me personally, it did a number of things. Probably the most significant thing it did was took me from a person who could give speeches at a kind of classroom local community college--even a university level class once in a while--and brought me up to the next level. I became someone who could prepare materials and present a training to a large group of people, handle questions of a fairly technical nature, and by the time I was done in the three years I was coordinating the team. You know, I was like the point person of the team in coordinating the information and whatever. So for me, it made a lot of difference in terms of my ability to communicate what I wanted to say, it taught me new tools for doing the work that I wanted to do with disabled people. It also allowed me to network with a lot of disabled women across the United States.

The primary communities that I worked with on the road were disabled women and parents of disabled children--those two communities. You know, basically, at every meeting we were meeting from breakfast until bedtime because somebody always wanted to talk about something in the movement. I got to get a feel for and get a cross section for and make networks with

disabled women who were working in different parts of the country on different kinds of issues. I got a feel for what parent issues were like because I was like the point person on parent issues for the team.

Jacobson: And what were you finding out about women's issues and parent issues?

O'Toole: Well, the parent issues were a little more clear-cut. The parent issues were that even though the law had passed in '74--94-142--school districts didn't think or believe that parents had any rights. And the sort of processes that were supposed to be being put in place with 94-142 really didn't happen and everything basically happened off of parents advocating for the children and being seen as bullies by school districts. Everything was a fight. Every single kid was a one kid by one kid by one kid fight.

One of the stories I really remember was a mom who had a kid with a significant enough disability that it wasn't an easy fix--she needed two or three levels of adaptations in the school. She was a good advocate, she was fighting hard for her kid, and she had been at it about a year. And one of her supposed friends that was in the school district system said, "You know, it looks like you're really stressed. Why don't you see this psychologist, he'll make you feel better. You know, it's really hard doing all these changes," so she did.

Well, from then on, every time she was in an IEP meeting or at a meeting talking about her child, they said, "Well, you know, we really can't talk to you now because, you know, you have a psychiatric problem." So they sort of created stress, then they created a solution for her stress, then they informed her that the solution that they provided for her stress that they had created in the first place was inappropriate and labeled her a psychiatrically disabled person. So there was a lot of that kind of struggle.

Also, parents tended not to be very organized. Because it was individual children and individual schools, there tended a lot to be fighting one by one by one. It was a very hard environment for people to make change in because even if they were part of parent advocate networks, which a lot of them weren't, it was still a matter of who's going to come to my school with my kid on this day and fight my fight with me. So there was a lot of frustration about that. And it was good that we were doing 504 training because 504 for some people was a better tool than 94-142. They offered different kinds of remedies.

For instance, 94-142 protected a disabled kid in a school environment, but didn't, for example, provide sign language interpreters for the parents--for a deaf parent during an IEP meeting or during a school play--and so people were able to see how 504 could be used to change schools in a more holistic way, other than just providing an education for one kid. It also got parents networked to disabled adults in a new way.

Jacobson: Wait, let's go back, because I don't understand. The 504 did not provide interpreters?

O'Toole: 504 did provide for interpreters. I'm sorry if I said it wrong. Yes, they did require that schools provide interpreters for parents and staff. In other words, the 94-142 just talked about the disabled kid, but 504 talked about the entire school environment. You know, if the scouts were using the school and your kid was a disabled scout or you were the scout master, then it was supposed to be accessible--that kind of stuff. So that was some of the stuff that was happening on the parent level.

On the women's level, a lot of the disabled women's community was hooked up with the feminist community at that point in time. There had been a lot of activism on the part of women's rights issues and women's rights were much more prevalent in terms of community consciousness than disability rights. Women had come to it two ways--either people like us had been disabled young and just as we grew up feminism came to us the same way feminism came to a lot of people in the communities and we got interested in it. Or women were feminists who became disabled and suddenly realized that there was a need to have this connection between the disability movement and the women's movement.

At that point in time there was a fairly strong information network in the feminist community. There were a lot of women's bookstores, there were a lot of women's newspapers both national and regional. The Womyn's Braille Press was very active at that time, so blind women and women who were print-impaired were getting feminist information. Feminists were involved in that effort. In other words, sighted nondisabled women were reading the Womyn's Braille Press, that kind of stuff. So once I would find people, it was pretty easy to figure out what the issues were and hook them up with each other or tie into mutual networks.

So for example, in 19--I can't remember if it was '79 or '81--one of the major publications in the feminist movement, Off Our Backs, which was a political newspaper magazine that

came out of Washington, D.C., did a whole issue on women and disability. You started seeing things like at the Michigan Women's Music Festival they had a disability area and a disability tent. There started to be this kind of crossover in network of people, both in the heterosexual women's movement and also in the lesbian community, so both things were happening and that was really exciting. And there was literature and there were publications. The late seventies, early eighties, were good times in terms of information for disabled women.

Gender and Disability Issues

Jacobson: But apparently that was not true for the disabled women's movement trying to hook up with the feminist movement, so can you talk about some of the issues that weren't being addressed?

O'Toole: Okay, can I sort of say all and go from there? [laughter] I mean, I think that's why I started with the positive because it was so much shorter than the negative.

Well, there were a whole bunch of issues. A significant one was that the disability movement had no gender analysis and had no understanding that disabled women had some issues that were substantially different than disabled men. For example, while you could go to CIL to get your wheelchair fixed, you could not go to CIL to find childcare or to get pregnancy information. And I don't just mean Berkeley CIL, I meant any kind of disability-based organization in the country. You could not get referrals to rape crisis centers--the basic services: you could not find out about where was an accessible gynecologist. Basic services which women with disabilities needed were not available in disability-based organizations of any kind, either service centers or national information hotlines or whatever.

By the same token, the feminist movement which was out there setting up rape crisis centers and was fighting with family planning, making sure that women had access to family planning and abortion and all this stuff, had no interest or concern about or access for women with disabilities. So, it was great that they had this local rape crisis line, but deaf women couldn't use it. And you know, in those days there was no relay service so if you couldn't use the phone and they didn't have a TDD, you just didn't have access to that service.

The women's shelters were not accessible--and that's pretty much still true. The women's organizations were housed in inaccessible buildings, and nobody had any information in braille or on tape, and the women's movement as a whole did not see this as their issue.

And a number of times, I mean, this happened at CIL: one time I was working phones at the Center for Independent Living at Berkeley and I got a call from somebody that said, "You know, we have this woman who uses crutches and she's been battered and we need to send her--we need a referral." So I said, "Okay, here's the local women's--the East Bay Women's--women's shelter." So they call over there, and battered women's shelter says, "Oh, no, no, no, she's disabled, she goes to CIL." And so then I called the shelter and said, "You know, we're not a service--we're not a battered women's shelter. We don't provide twenty-four-hour service, we don't provide housing. We're not a shelter, we're a nine-to-five Monday through Friday social service organization." And she said, "No, no, no, you don't understand. We don't do disability. And people with crutches, they just couldn't keep up and they couldn't do their chores." And I said, "You haven't even met this person." There was a lot of that.

Jacobson: Who did you get the initial call from?

O'Toole: In that case I think somebody from like the Berkeley Women's Health Collective called us. In some cases it could be disabled women. I mean, those kinds of things happened all the time.

And you know, disabled women saying, "Pap smear? I'd like a Pap smear. Where can I get a Pap smear?" And deaf women saying, "What is a Pap smear? Nobody's ever told me about Pap smears." So there were many, many, many layers of basically whatever disabled women needed that was about being a woman didn't happen.

Jacobson: And the medical physicians are saying, "Why do you need a Pap smear?"

O'Toole: Well, they're still saying that. Like, why do disabled women need mammograms? And a book that came out that I think we talked about last time, Toward Intimacy and Within Reach from the Seattle Disabled Women's group, which basically said, "We know nothing." It would say, "IUDs: here's the kinds of things that for able-bodied women are contraindicated if you have these medical--you know, if you have diabetes--if you have

this, if you have that." But it said, "For disabled women, we don't know."

Basically it was like every form of birth control was contraindicated for a large number of disabled women. The reality was, as Barbara Waxman said at that time, all it came down to was inference. We just said, "Well, we know this about this form of birth control, we know a little bit about that form of birth control for able-bodied women, and so we're going to guess how that may or may not apply to disabled women." And to this day I haven't found anything that really talks about women with disabilities. Did I tell you on the tape about the epilepsy birth control story?

Jacobson: No.

O'Toole: Okay, this would be like '76, '77, '78, there was a woman in the community, a straight woman, she was blind, and she was with a guy who was also disabled--I think he was a quad--anyway, her name was Jan. They were lovers and they were sexually active. She was an epileptic and she three different times showed up both pregnant and having seizures. I mean, this happened to her a number of times. I was in the disabled women's rap group at the time, so people would bring this story. And she was this very responsible, very together blind woman. I mean, there was no reason to suspect that it was anything except--she was being very dutiful about both her birth control and about her epilepsy medication.

Well, it turns out that that epilepsy medication and birth control pills nullify each other. They wipe each other out, certain forms of birth control pills and certain forms of epilepsy medication. So even though she was taking both the pills, the effect of taking these two pills in the same twenty-four hours was that she both had no protection from seizures and had no protection from pregnancy. And it took her three rounds before figuring out that this was part of the problem and to switch to another form of birth control.

And I sort of tracked this story and about eight to nine years ago I started seeing little bits of it buried in medical journals. And finally about--so this is 1998--I would say about six months ago, I was watching Dr. Dean Edell, a health watch segment on the local television station, and he was saying that he got a question about birth control. He said, "Well, you know, we know something about them and one of the things we know is you have to be careful about what other medications you're taking. For example, if you take them with certain forms of epilepsy medication--this medication

chronically prescribed for epilepsy--they wipe each other out." But I mean, it was twenty years. We knew that. We, the disabled women's community, knew that twenty years ago, so how many epileptic women have been put on birth control pills because that information was not available to them and had pregnancies that they didn't want. And you know, the whole thing's pretty traumatic. No matter how you look at it. So those were classic simple situations.

Then there were disabled women trying to get pregnant. I mean, Kitty Cone has that great story about living in Georgia. And if you wanted to have your tubes tied in the state of Georgia voluntarily--like she had a friend who had four children who did not want to have any more children, who for whatever reason found that the birth control methods at the time were not useful for her. She's nondisabled. And in order to get her tubes tied, she had to go through three medical reviews, she had to wait six months, she had to get her husband to sign a permission slip--all this stuff.

Kitty, in a routine doctor's visit, who is in a wheelchair, says, "You know, I'm wondering if it's a good idea for me to get pregnant." Two days later she's in the hospital getting her tubes tied. I mean, that kind of stuff--the assumption that disabled women should never be parents, should never have children, should never even think about it--that kind of medical stuff happened all the time.

That was sort of the message I think in the community as a whole, that the disabled community sort of said to us as women: "We don't want you to be women; your womanliness is not welcome here. You can be cripples, but you can't be women." And the women's movement basically also said, "Don't be women because we don't want to expand our definition of women to include women like you. And don't bring us your medical problems." The result was that we ended up with basically no services and no place to go.

To a very large extent that's still the situation today. I would say that it's still extremely difficult to find medical providers that have any knowledge or information about people with disabilities during pregnancy. It's hard to find people that have positive attitudes that disabled people could be parents; to provide and get the information and materials you need when you are a parent; to get this epilepsy versus birth control information, that's still hidden and buried. There are a few places. There's the disabled women's health clinic in Chicago. There are a few bits of information, but really, for the most part, shelters are still extremely inaccessible. And

it's still extremely difficult to get violence support services for victims who have disabilities of any sort. Not enough has changed. And what's changed the most is the networks. Women are more likely to be able to find each other somewhere; that part has changed. The newspapers and magazines of the women's movement have in large part gone away, but there are now some pockets of disabled women who are more visible and can be contacted, so that some people can find their way in. But it's still kind of an invisible underground network in most communities.

Jacobson: Right. There is also a problem with disability remaining in the news and only every now and then you see an article.

O'Toole: Yes. No, the disability community as a whole does not think we have a gender, does not think anyone has a race, does not think there are differences based on age, or onset, or even type of disability for the most part. You know, it's kind of like you read a disability magazine and it's sort of--

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O'Toole: So you know, you read disability magazines--whether it's Mainstream or New Mobility or the magazine that comes out of the National Association of the Deaf or whatever--and it's as if any issues of gender--there's just no assumption that we're talking about a population with a lot of diversity. Instead, there's sort of an assumption that we're talking about one type of person with an exact disability category. And usually it's a man and usually it's white, and it's rare that there's any deviation from that norm or from that perceived norm. When in fact, if you look at who is in the disabled community, there are more disabled women than there are disabled men; there are more people of color than there are white people. I mean, disability has a disproportionate effect, but that's not reflected in the magazines.

Diversity and Disability

Jacobson: Why do you think that is? Are we afraid to recognize it as an issue? Why is that?

O'Toole: I think it's--what I've seen in my time is two or three factors kind of coming together. One factor is the legacy of our founding of this round of disability rights, which is, you know, some white guys in wheelchairs and one blind guy who were

college-educated. And so that's going to attract--and that certainly attracted in the seventies--other white college-educated people who had mobility disabilities, primarily, and some blind people, who felt comfortable in that environment. So I think that that's one thing. I think that our founding, our base, is grounded in that reality and that's led us in a lot of different directions which shows us that even though it's Berkeley and Oakland, very few people of color were ever at CIL for years and years. Mainly because it wasn't a place that people of color felt particularly comfortable or welcome. I think that's one thing.

Another part of it is that most of us, pretty much all of us, grew up in environments or became disabled in environments where we were the only person with a disability. So we had a major experience of being isolated, of being alone, of being treated in a not equal way for lots of reasons. I'm thinking here of Shelley Bergum. She lived in Montana and she'd gone away to college and she got disabled.

Jacobson: How?

O'Toole: Spinal cord injury. She was a spinal cord injured paraplegic and they moved her back home. And her father and her brothers would carry her in and out of the house and I mean, so her experience of disability was being isolated, of being alone, of being totally dependent on other people. And when the disability 504 show came to town, man, she somehow got her ass to the training. She just jumped on that wagon and showed up one day--wrote us all letters, and basically showed up one day in Berkeley and said, "I'm moving." You know. She saw what she had and she saw what the future could be. So I think that for most of us, our experience was not so different than Shelley's, regardless of when we got disabled: the world around us was not disabled. The world around us was moving at a different pace in a different way, and who we were and how we did things was not of any value in that community.

So when we came to communities where the disability people started to come together, even though we came from lots of different religions and lots of different class backgrounds and lots of different stuff, we hung on our unifying things. We hung on our college education, on our whiteness, on our similarities of disability; that was a critical piece for us. It's like we finally found our way to community and we didn't want anything to break that up and so we would really struggle with trying to find common ground within in that. Because if you really think about who was here in Berkeley in those days,

it was a very heterogeneous community--all white, but very heterogeneous.

Jacobson: Very.

O'Toole: --in lots of different ways and interests. And if you look at that population now, twenty years later, people are--you know, you're writing, and I'm making movies, and somebody's doing counseling and someone else is doing research. I mean, we're scattered, but in those days we were all hanging out at CIL doing direct services, which is not really where any of us necessarily would have been if all choices had been available, but where we were because of the time.

Then I think that another factor is sort of the victimization factor, which is that one of the outgrowths of coming together as a community is realizing that what happened to us as individuals was really part of a bigger set of discrimination that was happening societally. It was both painful and profound that to have that realization. It was profound because we finally got the Ah-ha--you know, "The way that I've been treated and the way that I've been made to feel bad is not really about me as a person, but really about me as a person with a disability who's being treated in this particular way."

It was very painful because once you realized it was societal discrimination, you realized that there were things that you, individually, could do to mitigate it--like living in a community with other people that looked like you or having friends or whatever. But by the same token, you know, any day you go out on the street, it's going to happen again. And it's going to happen in new situations, and it's going to happen when you travel, and it's going to happen with people who don't know you. I think that that's a very painful piece of information to hold because, I don't know about you, but certainly as a kid I thought if I just do everything right, if I just am a good enough cripple, people will stop asking what's wrong with me, people will stop trying to cure me, and people will stop saying mean things to me.

I think certainly with polio, that's the push towards having less equipment and being in lots of situations where like I'm at a party, I sit down, I put the crutch away--you know, I looked able-bodied--and I just tried never to get up the whole time.

Jacobson: Yes.

O'Toole: That kind of thing. I think that understanding that it's discrimination and understanding that there's a process of oppression is an important realization. And what happens is sometimes we don't know how to deal with the fact that that's only one form of oppression and one form of discrimination. And when we start to hang out with people who have a different form of oppression, whether it's about race, whether it's about class, whether it's about age, we don't always have a way to integrate that because it starts to feel like who's more oppressed than who. If I say, "Okay, you have oppression because you're black and I have oppression because I'm disabled--you're black and able-bodied and I'm disabled and white--how do I mix?" American society wants you to fight with each other and measure your oppressions against each other as opposed to see that you're both basically suffering from discrimination. In fact if you really look at it, the discrimination is the same, which is "a hatred of other." You know, it doesn't really matter what other looks like. And I think that that's been hard.

Also, as white people, we grew up and were taught--I certainly was taught tons of racism. You know, my father doesn't allow any person of color in our house, I mean, that's just the house rule. And it's never been broken, and it's never going to be broken, and he's going to go to the grave without anybody of color ever stepping foot across his door--which makes my having a Japanese daughter kind of challenging. [laughter] It makes his old age kind of interesting.

But I think that the disability community has not done a good job of saying, "You know, we are disabled and that's an oppression we have, but men have more power than women in American society and we should talk within the movement about what ways do men have power in the disability movement versus women." We don't talk about where do white people have power versus people of color--I mean, I think we just kind of pull the blanket over our heads and just say, "We're all the same," and we're not.

And it's clear when I go to conferences and it's a bunch of white guys talking that they're not talking about what I want to talk about. Or if I'm putting a panel together and it's all white people, we're not talking with the people of color. And when I bring in people of color to talk, a different discussion happens and also a different--I mean, the thing I think that moved me from being so committed to hanging out with white people in the disability movement is that I remember how totally important it was for me to see somebody else who was disabled, just taking a stand--whether it was Judy Heumann

going up to the head of local HEW and just yelling at him and crying and saying, "We have rights and you have to give it to us." I mean, I could run at that point, or I could certainly walk, and for her, who couldn't do that, to be in his face was really--I thought, Man, if she can do it, I should be fighting harder.

When I watched people of color--when the workshop leaders were always white, that connection doesn't get made. Yet if I bring in Cheryl Green who's African American and I watch the black women in the audience look at her, it's their click, it's their C-L-I-C-K--the old feminist term about: "Ah-ha, somebody like me understands my reality." For me, that was the thing that moved me the most beyond thinking that it was okay for white guys in wheelchairs to be the movement leaders. We all need to make that connection and white people are not going to make it for people of color, and men are not going to make it for women, and young people are not going to make it for old people, and us old folks are not going to make it for the kids, you know. [laughs]

Jacobson: Yes, I'm very aware of what you're saying. I know when I go to conferences and see panelists and facilitators, who may be disabled but don't have cerebral palsy or speech impairments, I do get put off. I get offended in a way because I think we just get left out. I think that that's what you're getting at.

O'Toole: Right. And it doesn't matter which way you want to go with it and I think it's a disservice to the movement, personally, for us to hold on to that sort of narrow view of who's in the movement and who belongs. I don't think it does us any good, personally. And I think it's important for us to not accept that.

VI DREDF'S WOMEN'S EQUITY PROJECT, CORPORATE WORLD, COMPUTER NETWORK, 1980-1994

Women's Education Equity Project, 1980-1983

Jacobson: Let me go back to the Women's Equity Project [Women's Educational Equity Project] that you worked on at DREDF. What was it intended to do?

O'Toole: I had gone to Judy and then later to Mary Lou in the late seventies and said, "You know, I really want to work on education or women's issues, those are the only things that really interest me." That direction was what I wanted to move in, so initially Judy had some money for the KIDS project and I did work on that. And then eventually DREDF got money through the Women's Education Equity Act--which was part of the Department of Education. It was this tiny pot of women's money to look at equity issues for women and girls in education. And they applied and so we all sat down and talked about what I would like to do with that. My feeling at that point was we don't know anything. I want to know something about women with disabilities. I want to figure out a way to find that information about women and girls with disabilities, document that experience, and share that information with other people, so those were pretty much the goals.

Now, October 20, 1980, was when the grants were awarded. November 8, 1980, Ronald Reagan was elected president. And the Heritage Foundation came out with a report a few days after his election, which they had been working on for months, that basically said how they were going to change the government to be the Republican vision. It said, "We're going to get rid of the Women's Education Equity Act and cut all their funding." [laughs] So the whole time we had money we were kind of part of this thing that was under siege, but we did get our three years of money.

The first year what we did was a national survey. We sent out 10,000 questionnaires. We created a questionnaire asking people--women and men with disabilities--about their income, about their education, and about their experience. At that point the limitation we had was that the census data was not asking very much information and not asking any information about disability. So the only way that researchers were getting any information about disability was looking at health statistics, which a lot of us with disabilities don't show up under, or they're using labor statistics, which is who cannot work, which certainly didn't collect any of the people that worked at CIL. So we were trying to sort of end-run that and did a survey that was sent around the country through independent living centers, through disability organizations, through the 504 network.

We got back a whole bunch of responses that basically said that there were a lot of women with disabilities, there were a lot of people of color with disabilities, that women had a very disproportionately bad time in terms of economics and in terms of access to services. (There had been a study by the Department of Rehab reporting that out of every three women who came to them federally, they helped and sent home one out of those three as a "homemaker." There was another study that showed that even though people of color were a very high percentage of the actual disability population, that Rehab was overwhelmingly geared to white men: four out of five clients were white men. So we knew that the whole sort of system wasn't working.) We collected a bunch of information and we were able to start documenting that. That's what we did our first year.

Our second year we did two things. We wanted to share the information we had, and one of the other grantees from the Women's Education Equity Act program was a group called Educational Equity Concepts, which was based in New York City. They were primarily nondisabled women who had done a lot of work in terms of girls in schools, particularly young girls in schools, so we pooled our resources and put on, in June of 1982, the first national conference on disabled women and girls.

We put it on in Baltimore, so it was near enough to Washington, D.C., that we attracted the D.C. crowd, without being so close that they could just kind of drop in for an hour. [laughs] We brought together people from the government, from the women's movement, and from the disability movement, so that the keynote was like Gloria Steinem and Judy Heumann having a dialogue about women and disability. In fact,

Gloria couldn't come and so Letty Cottin Pogrebin came in her place. It was a very interesting--

Jacobson: Letty Cottin Pogrebin?

O'Toole: She was the assistant editor at Ms. Magazine and she's a major writer on women and Jewish issues. She came and said things like, "Oh, yes, my cousin is a victim of cerebral palsy," so every disabled person in the room went, "Eek!" Then Judy said things like, "I want the women's movement to take on issues like attendant care," and every nondisabled woman in the room went, "Eek!" It was a very interesting--we intentionally addressed the diversity of our audience and the separateness of our audience right from the beginning with this keynote about raising the issues, and then proceeded to spend a couple of days together working on those issues.

The other thing we did that we actually showcased at that conference was we created a book for disabled women and girls called No More Stares--S-T-A-R-E-S--No More Stares--that we worked on with Ann--her name was Ann Cupolo at that point. Ann Cupolo, Vicki [Victoria Ann] Lewis, and I did this as a joint project and spent the better part of a year and really looked at trying to make--the book was a really interesting challenge because I wanted it to be very accessible across a lot of different levels. I wanted it to be accessible to girls, so Vicki wrote a theme story that went through it about a girl with a disability. I wanted it to have lots of photographs for people that couldn't read, or for whom reading was not a useful way to get information--and also that meant that we could use it in preschools because it was just pictures. I wanted it to have lots of quotes so that there was not just one person's voice, but lots of voices from lots of different women and girls, so that for people for whom the pictures were not useful, where the text was more important, had a lot of different kinds of information. And then I wanted it to have lots of resources and so we had a very extensive resource section.

For a long time it was one of the few books really out on women and disability and certainly is still one of the only ones that has a lot of different levels of information, a lot of different ways to access it. I wanted it to be a book that wasn't a book in a traditional sense of a linear story from A to B--I wanted preschoolers and college kids to both be able to look at the same book and get something out of it. And for that I think we accomplished our goal. People who were very book oriented and very linear oriented hated that there would be quotes on a page with pictures on a page, and that the

quotes were not of the person in the picture. They wanted more congruity. But we grouped it in sections about work and about leisure and about friends and about discrimination.

And Bob Crow, the disabled designer, did the design for it for the book, and it was nice. It was very good and DREDF owns it and never published it and so it's long been out of print. I think I have a few copies. I'll donate one to the library. But it's around. You know, it was an important thing and we showcased it at the conference. So that's how we spent our second year.

Our third year what we wanted to do was take this information into the community and so we identified four sites and hired local women in those communities to find us a location, to find us the girls to do the outreach--whatever. And we provided training for girls from eighteen to twenty-four in four different sites. It was like basically camp. We sort of did a summer camp kind of thing for a weekend. And that was so amazing. I mean, we put together a team of California women to go in, provide the core training. That was matched by local women who came in and provided other classes, but mostly it was just camp. Mostly it was, "What does it mean for all of us, for disabled women, to live together, to work together, to eat together, for a period of three days, and to spend time together and get information from each other."

Jacobson: What was the content of the training?

O'Toole: Mostly we were looking at trying to give skills information and give experiential information for women with disabilities. So we would have leadership training workshops, we would have like a public speaking workshop, we would have a self defense class. Sue Sygall was one of the team members and she did a lot of sports kind of stuff, so she would plan like self defense classes that had people in power chairs knocking over trash cans. Kathy Martinez came and did a lot of work both on women of color, but also specifically leadership training skills. I brought Sonya Perduta, who's a nurse, so we could talk about health care issues and we would have sex workshops which was--you know, you had to not call them sex workshops then because of Reagan, but anyway, we would have sex workshops [laughs] and health care workshops.

Jacobson: What did you call them?

O'Toole: Health. You know, women's health, I think, is how we codified it. I'm trying to remember what all we did. I sort of gave the trainers a lot of latitude to sort of design their own

classes. People had workshops on media, and then the local community--like when we went to Minnesota, there's a very sophisticated disabled women's community there, so they came in and did a whole series of things on employment and on education. But the basic idea was that it was less important what the content of the workshop was; what was more important was that the disabled young women realized (a) that they were not alone, and (b) that there was a lot of ways to get information in their community for whatever their dreams were. We did a lot of dream work about what do you want to do, what do you want to be, how do you want to get there, what are the steps, what are the barriers, how do you figure that out, and who right there in this room can be part of the resource for solving that barrier.

Jacobson: And where were the four communities? There was one in Minnesota--

O'Toole: Yes, one was Pocatello, Idaho, because there was a woman that had lived in this community--that was Jean Marie--who was running the independent living center of Pocatello, and we had also done some 504 training there, so it was a community that we had some good roots in. One was Eugene, Oregon, and one we did in the Bay Area. So we had four of them. It was nice.

We traveled with our own attendants. I borrowed the 504 model in that we brought our own interpreters, we brought our attendants, and we brought our own team of people. Primarily, Marian Blackwell Stratton and I did all the logistics for it, and I did the curriculum. But I really liked it. I thought it was a very--and I worked really hard. A couple issues that I worked very hard on was making the team look to each other for support and resources because when we got there with the younger women, man, their stories broke our hearts. I mean, I still have nightmares from some of the stuff they talked about. I needed our team to be able to listen to the kids tell us about abuse and about institutionalization and about stuff that they really needed to--that they had never told people. And I needed the team--our people--to be able to sit and listen to them and then go and cry on our shoulders as opposed to what adults tend to do, which is say, you know, "Stop talking, I can't hear any more." It was, I think, it was an important piece of work that we did.

You know, we distributed copies of No More Stares. Harilyn Russo and Michelle Fine were doing a study at that point on young women and they came to one of our trainings and used our group as a population for their research. So we collaborated with others and we helped to strengthen disabled women's work

in the different communities that we went into. It was good. It was good for the women and it was good for us.

Jacobson: Was there a long-range impact?

O'Toole: Well, I think that it's easy to talk about and it's hard to document, if you know what I mean. I think if you look at any of the research that's been done on any oppressed community, you find--and I know WID [World Institute on Disability] just did a study a year or two ago about disabled leaders and what they found was that once people had made the transformation from "It's only about me," to, "Well, maybe it's not just about me," then finding a community--"Ah-ha! It's really about the way the world is structured. Discrimination is part of the system. I have to work to change it--nothing's going to change if I don't take action." Once you went through that process, people never went back. It didn't matter even if it looked like all they were doing was living a very quiet little life, you know, they were working, they were making--they were working on social change.

And that's what I think happened for both our trainers, for our staff people, for our kids, you know, for the young women--that we all showed each other just by our example that as women with disabilities we could do anything. We could put on conferences, we could write books, we could put on trainings, we could talk to each other, we could, you know, race down the hall with each other--. I remember this one-legged girl who had lost her leg--she was jumping on a train and missed and lost half of one leg--her and I racing down the hall. She was going to win, of course; she's a very good athlete, [laughs] I was not, but you know, it was about an experience that very few of us get, as women with disabilities, to think about and talk about and focus on women with disability issues and our commonality. I think that that has had a long-term profound effect.

And does anybody do a follow-up twenty years later with these kids? No. You know, all of the women that I trained--one of them died--all of the women that were on my training team are still working on women in disability issues. You know, Kathy Martinez put on the international women's conference in 1997, Sonya Perduta is doing a mammogram study with disabled women in Boston, you know, Lois Smiley is still doing work around women in disability as part of Deaf Women United. I mean, everybody's still out there, still doing work in the community. I'm still doing disabled women stuff, so I think that the work continues. I think that because it doesn't have organizational funding and never will, that it's a little

harder to kind of gauge it. I thought it was worth it. And I still get requests for the book.

The Corporate World--A Straight Job

Jacobson: What happened after that project, what was your next step?

O'Toole: Well, for me, it was clear to me by October of 1983 that the money for disabled women stuff had sort of dried up. From about '77 to about '81 there had actually been some money. There was a lot of money poured into sex and disability stuff; there was a fair amount of money poured into reproductive rights issues for disabled women. There was a lot of writing--there were some books. There were some early books on women in disability, but basically the money had dried up. And the feminist movement wasn't going to pick it up and the disability movement wasn't going to pick it up and everybody was sort of scrambling for funds and disabled women were a very low priority. I was tired. I needed to make some money, so I made the decision to take a break.

When the project ended, I left DREDF and decided to sort of switch gears and go to computer school and look at being a computer programmer for a few years and see if I would like it and what it was. I figured that computers were the wave of the future and I needed to kind of get my foot in the door with them, so that's what I did. I kind of took a break and spent a year going to the CIL computer training project which is now called what, Computer Technologies Project?

Jacobson: Yes.

O'Toole: Then I spent four years working for Wells Fargo Bank, and then left.

Jacobson: That's a very straight job.

O'Toole: Yes, very straight. Actually, what was interesting to me--this is just a little piece of economic information--when I was hired at Wells Fargo Bank, I was hired right out of school, so I was considered to be a grunt employee and was pretty much functionally a grunt employee. In other words, I was doing coding like changing dates on reports and changing the way the columns lined up--I mean, stuff like that. I mean, that was my job. And at that point, my opening salary as basically a brand-new intern employee, I was making \$4,000 more than the

director of the Center for Independent Living, who was responsible for an entire agency and the livelihood of thirty people. And so I thought, you know, this is--you know, I primarily went into it for the money. I primarily went into it because I needed a break from disability work and I needed to see if I could do a straight job. I needed to try and get some money together, and I was trying to get pregnant. I was sort of looking--I was looking at other things--I was playing basketball, I was looking at other things in my life.

Jacobson: What was it like being in that corporate environment compared to working in a nonprofit?

O'Toole: For me it was not satisfying. It was interesting to be with a group of people, all of whom made a fair amount of money, all of whom complained about not having enough money, all of whom really only had to worry about themselves and maybe their children. And most of them didn't have any interest in social issues whatsoever. It was interesting to be in that environment; it was not pleasant. I found it very disorienting to--Joe Quinn later said when he ended up following--he followed me in that path and he said, "You know, I just don't want to go to work on Monday morning and talk about my lawn." You know, it was like, that's a lot of what you did, just talk about your lawn, or talk about the ball game. I was much more interested in what was happening in the world of social issues. [laughs]

Jacobson: Did you ever talk about social issues? Did you ever bring--

Computer Network for Disabled Women

[Interview 5: October 21, 1998] ##

Jacobson: Corbett, when you were at Wells Fargo Bank, were you still involved in doing women's work?

O'Toole: Yes, I was doing two main things when I was at Wells Fargo Bank. One was I was involved in the disabled women's sports community. I was playing wheelchair basketball, and on a team called the Meteorites, which was a Bay Area team that did both local and national competitions. And then some of the players were also international players. And we were also doing mentoring of young girls who were interested in sports--doing work with younger women.

The other thing I was doing was trying to--I really saw the power of computers and I was really interested in helping the disabled women's community start to get on-line. At that point almost nobody had e-mail and yet lots of us were stuck home for different reasons--economics, or health or whatever. We certainly were very geographically diverse and it's very expensive to get us together. Between the technology to make computers accessible for blind women and also for deaf women--it's a totally accessible medium as long as they have a second language of English--I saw the potential of it to really start to network us. And so I talked to people.

I bought a computer in 1986 for home use and started to e-mail, started to learn the e-mail system. The woman who mentored me in that was a woman named Janina Sajinka who, at that point, was the computer network person at the World Institute on Disability when the World Institute on Disability was running their own Web site, basically--called WIDNET--W-I-D-N-E-T. That no longer exists but anyway Janina was there. I hadn't done e-mail and so she kept walking me through the steps and helping me get connected, because at that point it was kind of complicated.

I wrote a small grant to the San Francisco Women's Foundation and obtained some money to buy some modems and bought them from the SeniorNet people in San Francisco. I started giving them out to disabled women and girls and provided education and training on how to use computers in general, and more specifically, how to set up e-mail accounts as a way to push the disabled women's community to develop a communications infrastructure that it really didn't have.

It was a very significant uphill battle. The main issue that we encountered was, while the modem was free, the computer certainly wasn't. There were two major barriers. One was the economic barrier, which was very significant, which is how can people afford to have computers in their homes where they needed them. Some people had jobs and they had some computer access at work. But how could it be possible for every woman to have a computer in her home? The second issue was how to provide effective training for them when it's basically going to be kind of on the phone or long-distance. So those were the things that we pretty much struggled with for a number of years. It took a lot longer than I thought. I thought that we would all be computer whizzes by 1990 and I would say that I didn't really see computer literacy in the disabled women's community in a significant way until closer to '95.

Jacobson: You said we--who else were you working with?

O'Toole: That's a good question. I mean, there's always a 'we,' because you're never doing anything alone. There's always other people talking to you and helping you out and thinking about things. Well, Janina was a main support about it, Barbara Waxman had a computer at work and was working with people to create some networking, I don't remember who else was around. A lot of it was me, just kind of talking to people and giving them the modems and hanging out. But it's always part of the community --you know, I tell somebody, they tell somebody else, so there's always a community of people doing the work.

Jacobson: And how did you determine who would get the modems?

O'Toole: Well, we had the modems available for \$10, so almost anybody could get it. If they could catch up with me and actually get it in their hand, they could have a modem.

Jacobson: I guess what I mean in general was how did you hook them up, how were they available?

O'Toole: Well, a lot of it was word of mouth. A lot of it was just telling people, whether it was the Center for Accessible Technology, which was in those days called the Disabled Children's Computer Group, or telling the people at CIL. Every time I traveled I just brought a box and I left it behind. There were boxes of six modems and they came with software for PCs. Then we had gotten some discs--the Center for Accessible Technology had helped me get some discs--so, shareware--to make them useable for people that used Macs. So for instance, in 1992, Barbara Waxman and I did a conference in Los Angeles on Disabled Women in the Law and just brought modems and anyone who wanted one could have one. So just as I went places and as I did work, I took them with me. Like I said, it was very slow, but eventually--now the majority of the disabled women that are around have access to some kind of computer, whether at home or at the library or wherever.

Jacobson: Now, you still were at the bank when you started to do this?

O'Toole: Yes, I was at the bank until 1990.

Jacobson: And then you'd left the bank.

O'Toole: Right.

Jacobson: And what happened?

O'Toole: What did I do next?

Jacobson: Yes. Where did you go?

O'Toole: Well, I left the bank because it was clear that I was not able to do a full-time job anymore and support myself.

Jacobson: Why?

O'Toole: My polio had gotten much worse. I was walking until I was thirty and by 1990 I was thirty-nine and I really wasn't walking very much anymore at all. I was using a manual chair and what would happen is I would go to work and I would come home and I would just be tired all the time, so I was spending my weekends sleeping. My pain was increasing and my arthritis was getting bad, so my doctor and I sat down and said, you know, this doesn't make a lot of sense for me. So I went out on a disability from my job.

Since 1990--now it's 1998--I've been living on a disability check and Medicare and that kind of stuff and doing community work. It's really impacted how I work, you know, because I do a lot of community work, but I really try to do it project by project. I can take something on with a very short time limit, or I take something on--for example, I put on an annual conference for women with disabilities in June in conjunction with the Society for Disability Studies Conference. I did that in '94, '95, '98, and I'm going to do it again in '99, but it's something where, you know, whenever I have energy I can do it. It isn't something where I have to show up at a certain time on a certain day. Except for the couple of days of the conference, it's actually pretty much on--I can do it whenever I have energy. So a lot of what happened after 1990 was I realized that I couldn't do anything that required me every day to get up and physically attend to a task. I had to have some flexibility to do that, so I would just take on projects as they came to me.

One of the things that came to me was the California Women's Law Center decided that they wanted to have a statewide conference on women in disability and the law. They flew me to L.A. and Barbara Waxman and I decided we would co-chair it with them. And we worked for about a year--a year and a half. We were responsible for content and access and they were responsible for fund raising and we worked together to put on a conference on women and disabilities. That happened in 1992 and really was quite wonderful. So some projects were kind of big like that, some projects were kind of small.

By 1995--well, no, by 1993--the International Disabled Women's community had decided that we were all going to Beijing

for the United Nations Conference on Women. And nobody was coordinating the U.S. stuff and I was just praying somebody would coordinate the North American women. Nobody really did, so I ended up taking that on. That was a really big job for almost a year by the time I was done. But in the end we brought fifty U.S. women--mostly U.S.--a couple of Canadian women--with us to China for the women's conference. We were joined there by another 300 disabled women. So it's different kinds of projects at different kinds of times. Always talking to college students, always consulting with nondisabled women's groups.

For a while the Lyon-Martin Health Clinic in San Francisco had a contract where they were looking at how to make the center more accessible so Kathy Martinez and I were in there working with them about physical accessibility, attitudinal accessibility, training and that kind of stuff. So it's always something, as Gilda Radner would say. It's always something.

VII UNITED NATIONS CONFERENCE ON WOMEN IN BEIJING, CHINA, AND
POST-CONFERENCE ACTIVITIES, 1995-1998

Organizing Disabled Women's U.S. Contingent

Jacobson: Can you talk about the Beijing trip?

O'Toole: Sure. The Beijing trip--God, it had a lot of parts to it. It was a very complicated piece of work. I was coordinating with a woman named Cindy Lewis who works for Mobility International. Cindy was the designated staff person in charge of making sure the international women got hotels, housing, transportation, and got to Beijing. I was in charge of the U.S. women. And we both--Cindy had recently moved to Berkeley so we were both living in Berkeley at the time--well, wherever I was living in '95. I think I was still up north. Sometime during that year I moved to Albany. Anyway--

Jacobson: Go back. Where were you before Albany?

O'Toole: Well, from 1990 to 1995, I lived in a town called Cotati--C-O-T-A-T-I--California. It's a small town of 5,000 people in Sonoma County. I lived there for five years and while I lived there, I adopted my daughter. But I know we're getting to parenting stuff, so I'll save that part. [laughter]

I eventually moved back and in a large part moved back because I felt very, very isolated in a community of people where there was not a distinct and out front disability community. People were all like hanging out in the neighborhoods but not really organizing or activating in any real way, so most of the places I went, I was the only person with a disability that I saw that was part of a community. I found that everybody was like--I just found it a frustrating place to live. It was fun in some ways, but it was very frustrating in other ways. Anyway, so I moved back early in '95. I think like February or March of '95 I moved back. I

moved to Albany and the conference was actually in September, so I was living here the last six months before Beijing.

Jacobson: That's Albany, California. [laughs]

O'Toole: Yes, that's Albany, California, thank you. That is Albany, California, not any other Albany.

In Beijing--the decision to do Beijing was a pretty important one for me because it was really expensive. It was going to cost us \$4,000 for each woman. I was primarily responsible for the fundraising. A woman named Pat Chadwick worked with me on that.

I had also decided at this point to start filming the disabled women's community. We had been losing--you know, too many disabled people had been dying and I really wanted to start documenting the disabled women's community as I went to conferences, particularly the international women's community. The feeling I had was I could do the local women whenever I got around to it, but the international women were more difficult to find and get access to. In 1992, I had gone to an international conference in Vancouver called Independence '92 in Vancouver, British Columbia, and had really seen how the American disability movement really fit into a major disability community, and particularly a women's community, worldwide. The DisAbled Women's Network of Canada had hosted a women's day and it was wonderful to be in a roomful of women where we're all doing simultaneous translations for each other and hanging out and it was really quite amazing.

Beijing was to some extent for me a follow-up for that. I was really interested in taking women to Beijing who were not necessarily leaders of the movement. In fact, a lot of the leaders of the disability movement didn't really understand why Beijing was important. I was much more interested in taking women who were working more at the local level, and that's pretty much who ended up going. We did outreach primarily on e-mail, you know, sort of a combination of word of mouth and e-mail.

We found a group, a U.S.-China friendship group, that found us a hotel. We ended up staying at a hotel that was a military rest and recreation center that was also designed as a backup as a hospital in case of emergencies for military personnel. It was in the country. It took us about twenty minutes to get into Beijing from there and we took a group of disabled women there and the place wasn't very accessible. For example, I

couldn't get into the bathrooms. But it did have an elevator, which was a real asset.

Jacobson: How many women?

O'Toole: At that hotel there were like fifty of us. We had already had some significant problems. The Chinese government didn't want us to come--they didn't want to deal with the disability access issues. And the United Nations, which was legally obligated to provide access, had informed us to our face--actually, I was at a conference in New York about six months before Beijing and I specifically asked the head woman, who was the head of the whole delegation about disability, and she says, "Oh, yes, we'll be fine."

And afterwards her staff person came up to me and said, "You know, we're overwhelmed, we have too much to do, we're fried, there's no way that we're going to provide access for you in Beijing, so don't come." Well, you know, it was six months away and there were already 300 women from around the world planning to go so we looked at it from the historical perspective: we weren't allowed to go to Mexico City, and we weren't encouraged to go to Amsterdam, we weren't--you know, Nairobi had not been accessible, so this was the fourth one. We had seen that if we waited for them to provide access then they were never going to do it. And the only way to really get access is to show up and organize.

Jacobson: So Mexico City and Nairobi had their conferences?

O'Toole: I missed the very first part.

Jacobson: Mexico, Nairobi, and Amsterdam had their own--

O'Toole: When the United Nations declared the Decade of Women, they kicked it off with an international conference in Mexico City. And then I believe the next one was in Amsterdam. It might have been Copenhagen, but I'm pretty sure it was Amsterdam. That was five years later. Five years after that, like '90, it had been in Nairobi--so this was fourth one.

Jacobson: And the Decade for Women spanned--

O'Toole: '80 to '90.

Jacobson: Okay.

O'Toole: So this was a post-decade event. It was like the fourth United Nations conference on women.

Those kinds of conferences have two tracks. There's an NGO track--a nongovernmental organization track--and there's a governmental track. The idea had been that there would be regional conferences that would create discussion and raise issues, that those would get consolidated into one international kind of platform, that then would be handed over from the NGOs to the governments to negotiate. The ideal is that the governments discuss and decide about these documents and make on-paper commitments--there's no force of law behind it about the rights of women--and that's kind of the process.

What had been very striking to me was that at all of the regional conferences around the world, there were very powerful statements from disabled women. Even though none of the regional conferences were designated as accessible the African women--there were like 200 African women with disabilities that showed up at the African prep-conference--had a whole section of the document from the African region on women with disabilities. The same thing happened in South America, the same thing happened in the Far East. I mean, it was pretty amazing that the disabled women's presence was so profound in all these documents. So when the documents started to come together, it wasn't a few disabled women saying, "Include us," it was that the women from around the world had already said disabled women need to be a part of this document.

Jacobson: How did you get that type of information? Most of the time that information about disability is buried somewhere and nobody really notices it. How did you find it?

O'Toole: Well, one of the things that happened is that the international women's community--at the very first conference in Mexico City, a lot of the representatives who attended were men from governments, so one of the things back in whenever that was-- '68 or '70--the women realized--I'm sorry, I'm off. One of the things the women realized in Mexico City was that if the women's organizations didn't take leadership and control about women's issues, then the governments were just going to treat us as second class citizens and let the traditional bureaucrats make decisions on our behalf. So there had over the years developed a series of international organizations: the Women's Economic Development Organization, an organization that Bella Abzug and a number of women from around the world had set up; the Center on Global Women's Leadership, that Charlotte Bunch directs at Rutgers; the Sisterhood Is Global Group, which rotates leadership that Robin Morgan is a part of--I'm naming some of the U.S. women, but they're actually all international organizations. They would pressure, for example, the United Nations to make these documents easily available and

accessible. It was 1994--a lot of this stuff was available on-line.

So that what would happen--for example, Susan Sygall was supposed to attend a meeting hosted by WEDO--Women's Economic Development Organization--in New York for all of the NGOs--representing a group of NGOs from around the world. They hosted that on Long Island. Susan couldn't go because her sweetie had a heart attack and so she sent me in her place. So I'm on this committee of women that are looking, physically looking at all these documents from the five regions. So that information was available because there was going to be another meeting in a couple of months--we were meeting in December of '94--there was going to be meeting in March of '95 called the Preparatory Conference--Prep Conf--that was going to take all five documents and synthesize them into one document. So that information was fairly readily accessible.

The International Women's Tribunal also had information on their Web site, so that information was floating around and we just had to ask for it. There wasn't at that time a disability group that was necessarily saying, "Here's the disability information." We were just busy fighting about how we were going to get around to Beijing and how accessible the conference was going to be.

Jacobson: Where did the money come from for you to go to the preliminary meetings?

O'Toole: Well, the only preliminary meeting that anybody attended was the one I went to at WEDO, otherwise we didn't get to go to any of the preliminary meetings. The regional meetings were women that lived in those areas. You know, in Africa I don't know how the women got to the conference, but in the U.S. I think--actually the Prep Conference for North America and Europe I think was held in Europe. I don't think it was held in the states, so I don't know who went from the disability community. But the document had disability information, so I'm assuming whomever it was, the women in closer to that site attended. We mostly decided to focus our efforts on actually taking action and being busy when we were actually in Beijing at the conference.

The money was hard to come by. The women's community did not see taking disabled women as a critical part of their work, and very few organizations even though they had lots of money saved a slot for disabled women from their community. Occasionally I would meet a woman who was funded by a traditional women's organization as part of their group, but for the most part that didn't happen.

Mostly I was responsible with Cindy for finding people housing and getting that set up, and then beyond that people were a lot--we made it clear that groups had to fund raise themselves. So there was a group of six women in Eugene, Oregon, who made T-shirts and had fundraisers and did bake sales and did car washes and, you know, went on local radio and got the word out.

Down here in the San Francisco Bay Area we made T-shirts, we made bags--Pat Chadwick designed us a beautiful "Disabled Women Changed the World from Berkeley to Beijing" slogan with images of disabled women on a globe. She did a beautiful design and we used that for T-shirts and tote bags we sold. Simi Linton knew a guy who had a family foundation and he gave us \$4,000. Harilyn Russo was sitting on the board of the Sister Fund and they gave us \$18,000. I was sitting on an advisory committee for the American Friends Service Committee and they gave us \$3,000.

And mostly, pretty much all the money we raised was--a little bit of it we could use ourselves, but for the most part we needed to bring our own attendants and we needed to bring our own sign language interpreters because they were not going to be provided. We were told that there would be no interpreters or attendants, so we needed to raise money for four people. So before I said hello in the morning, I needed to find \$16,000 and four people that would be willing to go with us and work for free in exchange for the trip--I mean, but it was work for them, it was not easy.

The money that we raised over that--I forget what all that adds up to, but we were able to give women \$500 scholarships or \$1,000 scholarships--but that was also from our fundraising, to offset some of the cost.

We also made the decision that we wanted to document it, so Suzanne Levine, a professional photographer, went with us and did still photographs; Pat Chadwick brought her radio equipment and did radio interviews; and then Jennifer Bregante and I took our video equipment and did video interviews with people. We were there.

It was very inaccessible--what they told us was true. You know, we couldn't get in the disability tent the first day because it was on a concrete platform and the sidewalks were all brick that had not been put together, so the minute it rained, which it did rather copiously, nobody could get over anything physically. There were 5,000 workshops over a ten-day period, so there was an average of 500 workshops a day. We

could get into none of them. There were seventy-one tents and other meeting areas. We couldn't get into pretty much any of those. So even though we were at this conference of like 35,000 women, we mostly couldn't go to them--they mostly had to come to us.

##

Jacobson: So women came to you.

O'Toole: Yes, a lot. You know, because the weather was really warm--when I say tent, what I mean is a concrete slab with a roof on it, but no walls. So we were in this back area for the first couple of days and then protested pretty vehemently about the lack of access at the conference as a whole. We were the first group--it was so Chinese--the Chinese designated a demonstration area where you were allowed to have demonstrations [laughs] and you weren't allowed to go anywhere else. We, of course, couldn't get to the demonstration area, so we just demonstrated wherever we happened to be. [laughter] We demonstrated rather vehemently. Actually, we made CNN back home, so people knew we were alive. [laughter] And were able to move our tent from this back area where it was very inaccessible and very difficult to get to, over right near the McDonald's tent, forward to a place that was much easier to get access to.

Only some of our group used wheelchairs. The women that were not in wheelchairs, the women that did not have significant mobility disabilities actually were able to get around a lot better than we were. There was quite a bit--we basically--the Chinese had sort of set it up that we took over this town, so you know, you were in their elementary school, and you were in their county buildings and stuff, so you took over this whole section of a town.

Jacobson: Did the women who used wheelchairs take manual or power chairs?

O'Toole: We told everybody to take manual chairs because we had no guarantee of access. Two of the women chose to take scooters but both of them could walk some in case of what happened.

Our transportation was a bus where they just laid down like a steel ramp on top, from a regular bus height down to the ground--so you can imagine how steep it was. We would just have people push wheelchairs up and down. When you got into a van, there were no tie-downs or anything, so it was just a big bus full of people sitting sideways and hoping that you didn't kind of crash into each other.

Like I said, two women brought power chairs and they were able to somewhat get around. But they decided for each one of them that that was better to have a power chair some of the time than not have any mobility at all, so that was the decision they made. Everybody else brought push chairs.

Like when we went to the Great Wall of China and it's all steps, [laughs] you had to bring a push chair because it was the only way to carry you. They would carry you up to different landings at the Great Wall, you'd take some pictures and then they'd carry you back down. That kind of stuff, you needed to have a push chair for that.

But what one of the interesting side effects of this conference was--traditionally in the U.S., if we want to go to the National Organization of Women conference or whatever, we would fight with them over access. They'd see us as the bad guys and we'd see them as the bad guys. What happened in China is that, for the most part, most of the women we were dealing with were not part of the problem, so they saw themselves as sisters and allies and wanted to become part of the solution. I think it was a really transforming moment because the American women were really quite strong and quite powerful about disabled women's issues. And when you read the follow-up material in various feminist publications from China, almost all of them mentioned the issue of women in disability and lack of access.

And such things as when Hillary Clinton needed sign language interpreters to give her speech, she came to us and asked to borrow our interpreters. When Madeleine Albright had to give a kind of plenary speech for the world, she had it in the disability tent so the disabled women could participate. So there was really some spectacular kind of transformational changes happening that really hadn't happened in terms of the collaboration of nondisabled and disabled women's movements.

Recognition from Nondisabled Women

Jacobson: Why do you think that was?

O'Toole: I think that there were a couple of factors. One of the main factors was that the women who were stepping forward to be our allies are women that traditionally are the leaders of other conferences. In this case it wasn't their conference and it wasn't their problem to solve. Do you know what I mean? We

weren't yelling at them about access, so they could be our buddies. They're like, "I know this problem. I understand this problem." I think that that was significant.

I also think that disabled women have worked really hard with nondisabled women for a lot of years to educate them about the issues. I feel a lot of women's communities are very sophisticated about disabled women's issues, even if they don't always plan and provide the appropriate resources--like they don't have sign language interpreters for their plenary speeches kind of thing. But they know that they should and they know what the issues are. It was nice for them to be in a position of educating their other nondisabled sisters about what the issues were, much the same way that, whenever you're an ally for another movement, you can educate people who are not in the movement about what the issues are--kind of bridge-builders.

I think they really were moved by the fact of how difficult it was for us--that it was not subtle; it was not like a little problem. They were all climbing four flights of stairs to go to workshops on disabled women, for example. So it wasn't invisible in any way, shape, or form. It was quite visible and quite--I was just talking to a woman who was writing a report for the Sister Fund the other day and she was saying one of the things that struck her in Beijing was that you couldn't ignore the problem of disabled women. Every woman there came away with an awareness of that issue in a way that they had not realized before.

I think that worldwide that was the reason to go. That was the reason to be there and that's what the international disabled women's community understood about why it was worth doing--as well as networking. I mean, always networking disabled women to each other and making new connections and making the community stronger.

One of the significant things that I found was that--you know, most of the women I said that came from the U.S. were women that were local community women. They were women that were active on a local level, but not really necessarily active on a global level. We all develop myths about how easy or hard other people's lives are. And it was wonderful to see these local women from the U.S.--where the myth American women had was, "My life is so much better than your life"--sit down with a disabled woman from Africa or Asia or wherever. For example, a disabled woman from the U.S. would sit down with a disabled woman from Uganda, where they have an employment workshop for disabled women, childcare for disabled women, and a national

really together disabled women's organization, and the Ugandan woman would say to the U.S. woman, "Well, you guys have all this money and resources, so what do you have?" And the U.S. woman's like, "Duh, we got nothing." So it was very telling.

And I think it was also very educational that people realized that the problems facing disabled women are much more economically driven and much less racially driven. The more developed the country is and the more resources there are for all of the people, the easier it is to get basic access to services for disabled people. And the more impoverished the country is and the more that the services are reserved only for people with access to private funds--for example, it was shocking to most of the U.S. women that in most of the countries of the world there was no access to education for anybody, not just for disabled women. It's not just about, is there a special ed school, it's that you can only go to school if your family can pay money. Period. End of discussion.

The chances of a disabled mother being able to send her children to school or the likelihood that she was ever sent to school is very, very small. U.S. women who never thought about issues like illiteracy, and certainly didn't think about the impact of the World Bank on the economies of developing countries and that cycle of global economy, came away from that conference really saying, "I understand disabled women's issues on a whole other level than I understood them before." And also, by the same token, the disabled women who were there from all over the world, particularly from other countries had pretty sophisticated regional resources and so whatever we gave them, whatever information we shared, got shared across a vast network. And I think that was profound.

Jacobson: Who was responsible for bringing the workshops? Did every group have their own workshop or how did it work?

O'Toole: The 5,000 workshops were because people submitted official forms almost a year in advance to the NGO office of the United Nations to say, "I want to do a workshop on this issue." They were assigned a space and a time and a place.

In addition to that, seventy-one different groups had tents of their own, so that the older women had a tent, there was a spirituality tent, a Latin American tent, and then people from those communities planned their own workshops so that disabled women had stuff going on all the time. And it was a combination of different things. Like in the U.S., we made some decisions about information we wanted to share. DPI--Disabled Peoples' International--a women's committee--scheduled

time for people to give speeches. SHIA--the Swedish Handicapped Information Agency, which is also a funding organization and funded a lot of southern hemisphere women, would have workshops and information.

Then there were just informal networking kind of things. People would come over--some of the musicians realized that we couldn't go to their workshops, so they brought over instruments and just led music jams or people would have dance lessons. [laughs] In addition to the 5,000 workshops, in each tent there were both formal and informal workshops that happened.

Jacobson: It sounds like there was a lot of networking.

O'Toole: Oh, yes, tons of networking. For the disabled women that was the main thing, both with women from their own country and with other disabled women from other countries.

Jacobson: Okay, if everything was so inaccessible, how did you get to nondisabled women? Did they just come over?

O'Toole: Well, they came over, and we could walk in some of the public walkway areas. And you have 35,000 women in a square mile kind of thing. Think of a college campus, essentially, in terms of how basically if you just hang out on a corner, eventually the whole campus will pass you by. So some of it happened that way. Some of it just happened that we would be hanging out and people would come by us and people would make connections with people from their countries, or people would stand outside the tent. In some cases some of the people who were monolingual Spanish--there were a couple of women who only spoke Spanish with us and they would just hang out near the Latin American tent and they would catch people as they came and went. Or people came to us. I mean, all of the above.

Jacobson: Now, with the disabled women's workshops--were they mainly disabled women attending from all over the world or did nondisabled women come in also?

O'Toole: It would be more disabled women than not. But lots of people have connections to disability: old people who had canes, or women who had cancer, or women whose mother had cancer, or women who were parents of disabled children, or women who were caregivers for their elderly mothers or grandmothers. So there was a cross-section of who crossed our path and was interested in us.

Or they were funders trying to understand what the issues were. There were a number of funders trying to see what issues were not being funded in different communities around the world and they would pop by the disability tent.

Or they were media people trying to understand what the issues were that they wanted to get us. So it was an interesting cross-section of people that wandered through for different reasons and stayed for however long they stayed.

International Unity of Disabled Women

Jacobson: What were some of the highlights?

O'Toole: Well, at our hotel we had an evening of performances by different women in the group--oh, actually one of the highlights was that--this was tied to that--the Mobility International people in conjunction with the international disabled women's community had decided to put on a one-day conference. I had proposed the idea that we use for SDS [Society for Disability Studies], which is to put on a pre-conference day of disabled women. So they decided to put on a pre-conference day of disabled women at our hotel, which had a big conference room and a big meeting room, outside Beijing. And we had a room [laughs] it was probably--it was not very big, and we had crammed 200 women with disabilities into this room.

Jacobson: Oh, incredible!

O'Toole: And it had a tin roof, which will become critical in a moment, and up front we had our microphone system. But we didn't have translation, you know, any kind of formal translation, because it was all sort of shoestring budget. In the morning, different people gave speeches about, you know, the state of the world and the state of disability information in the world, but we had thirty-seven different languages in the room and what would happen is--basically you learned to talk in paragraphs. So you'd talk in a paragraph and then you'd pause and then all around the room you'd hear "phphphphphppph" as the persons in little groups of threes and fours would have the information that was just given simultaneously translated by their friends. Then people would ask questions, and then you'd talk in another paragraph.

So you're having thirty-seven languages going on in this room where we're like shoulder-to-shoulder, you know, bumper-to-bumper. In the morning we did it all as one--we did kind of lecture style, and in the afternoon we had people in workgroups talking about what you want the women at this conference to know about--this was before we realized how inaccessible it was going to be--about health or about education or about the law or about young women, in different groups. And then we had people give reports back.

I think, for me, that was amazing to have 200 women--and it started to rain in the afternoon and it just poured rain on this tin roof and we were just inside, gabbing away, chattering away, 200 women sitting in the same room--now we're having multi-lingual workshops, you know, of fifteen or twenty women at a time, trying to speak five or six different languages and talk about the same topic. So the reports back got a little interesting, but for me, that was a truly wonderful, amazing beautiful day. I have a beautiful picture of Meecha and I, my daughter and I, sitting outside with our bare feet in puddles, actually in the puddles outside the thing.

The other thing that had happened was the sign that the hotel had made for us was, "The International Women with Deformities Conference." After we took about ten photographs of it, they realized that maybe this really wasn't the most appropriate naming. At the end of this one-day conference, all 200 women just stood outside in one big row and we took some photographs and videos and it was just pretty amazing, it was pretty amazing. You really felt sisterhood in a way that you don't usually get too many opportunities to do that.

Post-Conference Impact on Disabled Women

Jacobson: What do you think the impact of the conference had and is having today? What year was that again?

O'Toole: Ninety-five, September of '95.

Jacobson: Ninety-five. So in the past three, almost four years, what impact did the conference have?

O'Toole: I would say a lot, actually. Prior to that, particularly through organizations like DPI, women had been able to come together somewhat in a regional fashion. So there had been sort of identified leaders--women that were committed to women

and disability issues, doing leadership in different communities; but because of economics, and stuff, they didn't very often have opportunities to meet with each other in the region or even meet with each other internationally. The entire arch of the United Nations work, from the regional meetings where documents were developed to the Prep Conference to Beijing, involved a whole lot of disabled women. It got a lot of women talking about how is disability a gender issue and what are the issues, and got a lot of momentum going, which was the intention, actually. Because if we had ignored it as we had Mexico City and Amsterdam and Nairobi, we would just be out of the loop.

I also think Nairobi had helped the African disabled women get organized because it was on their home turf--and they were not particularly included. So that process got a lot of people talking about women's issues.

What happened in Beijing is every woman there realized that she was part of a world community and that she was not alone. It didn't really matter how much the people at home said this was not an issue, there was no funding, you're crazy to think there's a problem, whatever. That's a critical piece for keeping women going--for keeping anybody going--is having people who believe them and listen to them and honor what they're saying.

The second part that was important about that is that there are a lot of problems going on and a lot of women talking about pretty significant issues of violence, of rape. Many women in poorer communities, whether they're in the U.S. or they're outside the U.S., are dealing with some pretty horrific situations where there is no protection and where they are the only person who (a) sees what's going on and (b) is trying to make a change. It's an enormous, enormous uphill battle. When I asked people about violence, the stories I got back were, I mean, spine-chilling instances of horror. These women are dealing with that every single day.

In a lot of the African countries, particularly in southern African countries, they're dealing with issues like AIDS, so the devastation and the levels of economic problems and the levels of social problems are pretty significant. So for women to be able to come together and to talk about what's really going on and get heard was really important.

The second thing that was really important is they got information. Information is so hard to get about women in disability issues--about birth control, about violence

prevention, about education, about how somebody else is solving a problem that you're trying to figure out. So that was a whole other round of resources and information.

Also, a lot of people by '95 had e-mail, so we had started in the Bay Area what we called CAL-WILD, the California version of the Women's International Linkages on Disability, WILD. That has turned out to be the main listserv for disabled women worldwide. I mean, pretty much all the information on women in disability comes through CAL-WILD and there's a whole network of international women that receive that information and post information to it. So out of Beijing, women got new information, they got strengthened networks on a regional and an international level, and a communication network was established. Suzanne Levine ran it from the beginning until mid-2000.

There was a lot of money put into post-Beijing activities and Roseangela Berman-Bieler and Kathy Martinez--Roseangela's at the World Millennium production, and Kathy's at the World Institute on Disability--went after funding, went after post-Beijing funding as did the Mobility International folks. By the summer of 1997, thirty-four disabled women leaders from around the world who had been identified in Beijing were brought to Eugene, Oregon, for a two-week leadership intensive training program around skills development, fundraising, and different issues that they wanted to address. Then those women plus another almost 600 women--so I think it was like 614 women all together--came together in Washington, D.C. for an international women's conference on women in disability. That was the next big kick.

Leadership Skills Development

Jacobson: And you went to those conferences?

O'Toole: Right, for Beijing I was involved in working with Mobility International to structure the curriculum, to plan the disabled women's conference day--the disabled women's symposium day. Then for the work that was done in '97, I was involved with Mobility International in planning their curriculum for the women's leadership institute and also, to work with Kathy and Roseangela at doing some workshops for the big international forum on women with disabilities.

Jacobson: Tell me about--how did you start to help them develop skills?

O'Toole: Well, I'm trying to think about how to explain it. It's a fairly simple concept, but it's a little tough to articulate. I think there'd have to be three components. One is that the woman has to believe that she's a leader in the sense that she's somebody that can pass the information on, so that if you give her something, she's committed to passing it on. Secondly, the woman has to know in her mind, sort of know who she's gathering this information for; she has to feel like she's tied to a community or a constituency that needs information. So as she's in a learning curve, she's listening with some kind of intention, it's not all washing over her like it's about something else. Thirdly, she has to commit herself to actually learning material, like gathering the information, whether it's on paper or whether it's on tape, or whether she's listening or taking notes; it doesn't matter how--but that she's committed to learning new information.

I think if those three factors are there, that anybody can learn anything. And it isn't about your disability or your cognitive skills, it's really about those three things. My experience is that if I train a woman where those three factors are present, that every woman they touch is good for 100 other women because she's passing it on.

Jacobson: Do you think those factors have to be present before the women come, or are they something you try to develop at the training?

O'Toole: Well, I think there's two things. I think that the level I work at is pretty much leader to leader. I don't tend personally to do that much work. I do it occasionally but I don't really tend--certainly not in a conference setting. Well, it was interesting, the '98 conference was very much like what you're saying, in the sense that it was a lot of people who were new to the movement, who were new to disability, who were really only looking for information for themselves.

Jacobson: Where was that?

O'Toole: That was in Oakland. That was the '98 Disabled Women's Conference that was pre-SDS. We did a lot of local outreach for that and we got like twelve women who were developmentally disabled. About 65 percent of the women that came to us were women who had never been to anything on women in disability before, so, no, they were not women leaders in the community, no, they were not. They did not have an identified constituency that they were information gathering for, they were basically gathering information for themselves.

I call that the seed-planting stage. You know, they came to the conference, which meant they were fertile ground and they were ready. They were hungry for information. What they took away from the conference was some seeds of new information, new ideas, whatever, that will grow. And how they grow and where they develop, I don't know. They may end up, you know, being leaders on women in disability, they may end up being, you know, accountants at a bank. It doesn't really matter. They came for something they needed and they took away something that was new information. I think that's a valid kind of training and that's a valid kind of learning but I think it's a very different kind of learning.

In fact, for '99 that's the issue we're struggling with is actually providing different tracts for people. For people that have more expertise and information, providing them a more theoretical track where they're beyond their own personal issues; they're dealing with community-based problems as opposed to individually-based problems and looking for community-based solutions as opposed to individually-based solutions. So no, I think anybody can learn anything, but if you're talking skills development, it's much easier if people are beyond their own personal experience. It's hard to learn when you're only thinking about yourself because then there's a lot of information that you're not capturing that other people do need you to know.

VIII DISABLED LESBIAN ISSUES, MEECHA'S ADOPTION, AND MOTHERHOOD

Disabled Lesbian Issues

Jacobson: I understand that you've been doing a lot of writing and speaking on disabled lesbians. What are some specific issues that are different--

O'Toole: For disabled lesbians versus other disabled women?

Jacobson: Yes.

O'Toole: Well, I think that the issue of cultural invisibility is very profound, that disabled lesbians--and disabled gay men, as well--don't exist as even a concept inside the disability community culture. What I mean by that is that when you call an independent living center and ask what gay services in the community are wheelchair-accessible or provide interpreters, they don't know. When you call up and say, "I need a referral to lesbian health care," they can't tell you.

In fact, there was a NCIL--National Center on Independent Living--conference that was held in Oakland in 1992, I believe it was, and I led a workshop on queer issues. I thought it was going to be basically subtle stuff of everybody who's queer that doesn't want to be out in the world but is queer show up. Instead who came was--some of those people showed up, but a lot of people showed up who were like independent living center directors, because that's who comes to NCIL, the administrative staff. They were basically saying that their staff--you know, this is the AIDS crisis--this is 1992--that if someone called up and said they had AIDS, that people were hanging up on them and refusing to provide them with services. Their people said, "We don't serve gay people here," that the level of homophobia was pretty significant and that they as administrators didn't, quote, "know what to do with it." I mean, they were tolerating

a level of homophobia that I don't know that they would have tolerated if it had been race-based or age-based or sex-based.

So one of the issues for disabled lesbians is that the disability community doesn't think about, acknowledge, or deal with disabled lesbians, and doesn't have any information or resources for them.

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Jacobson: We were talking about lesbian issues and disability.

O'Toole: Yes. Also, the disability community doesn't really expect or provide any information about lesbians. And to a larger extent, the lesbian community has created services that are not accessible to women with disabilities.

Although, I have to honestly say that in general the lesbian community, of the communities I work in, has been the most responsive about dealing with disability issues, much more than the generic women's community, much more so than a lot of other political communities. You know, early on they were the ones providing access in terms of communication and access like sign language interpreters for performances or telling you whether or not something was wheelchair accessible. The lesbian press has probably published more on disability than most other community presses have done over time. As long ago as 1981, the publication Off Our Backs was publishing stuff on women with disabilities.

So, over time, I would say that the lesbian community in general has been more responsive. Still, a lot of the services they've created--like a lot of times lesbians were actively involved in setting up women's shelters, or setting up rape crisis hotlines, or a lot of other activities that were not accessible. And it's still pretty difficult to call lesbian services and say, "I need disability-specific information," and be able to get it. So what it means is that disabled lesbians are sort of in the same place that we basically have pretty much no place to go for information that's a more generally available service. What you start to find is that disabled lesbians, in order to get either health care information or gynecological information or whatever--about safe sex for lesbians or how disabled women use safe sex techniques, for instance, when there may be a physical reason that using a dental dam is difficult or whatever--

Jacobson: Using a what?

O'Toole: Dental dam. When you want face-to-vagina contact, oral sex contact, for straight people or for lesbians you can either cut a condom and hold it, but it's very slippery, you can cut a glove and use that, or you can use something which dentists use which is called a dental dam. It's a piece of latex--a rectangle of latex--to put over the area, because what you're trying to do is prevent fluid transmission.

I know, it sounds strange to most people, but see, straight people don't do that. I mean, straight people don't use that stuff for the most part, even though they should. They think about condoms, but they don't--they think about protecting the man--it's sort of classic sexist health care--but they don't think about how to protect the woman.

Anyway, so if I'm a lesbian and I need to find out what I can use for safe sex and I may need some information about how to adapt something for me--I can't get a glove on my hand, so how do I do manual stimulation if I can't use a glove, what are the other alternatives?--I either have to call up a straight place and say, "I need to know this lesbian sex information," which they may or may not know, but, "I know you're a disability sex place and you can tell me that," or I have to go to the lesbian community and we have to try to guess about how to figure it out. But in either case I'm not getting the information that I need.

Often disabled lesbians, like other women, are not getting good health care. I mean, there were some studies in one of the articles I wrote, that said when people don't feel safe with their health care providers, they don't get good health care. They go less often, they don't tell their health care provider their concerns, the health care provider doesn't ask--I've never once, ever, in all my health care ever had anyone say, "Okay, and do you need information on this or that or that or that?" And with one of those being lesbian sexuality information or lesbian health care information or whatever. That just doesn't happen.

So what it means is that disabled women, in general, are at higher risk for health care stuff because we're not going for pap smears, we're not getting mammograms, and we're not doing breast self-exams. Disabled lesbians are even more likely on that level to have problems because usually we're women that often don't have birth children, haven't been pregnant, and we're in other high-risk categories. Some studies are saying that lesbians are in a higher risk category for breast cancer, for example. The fact is it puts lesbians in higher categories and tends to put all disabled women in high risk categories, so

if you're disabled and a lesbian, I'd say health care is a pretty significant problem--services in general.

There are always these assumptions about--and some of the disabled lesbians have written about this--that, you know, the only reason you're with a woman is because you couldn't get a man and if you could get a man, you would do that. Actually, there was some pretty bad research done a couple years ago where that kind of question was asked: have you ever fantasized about being with a woman. And if the woman said yes, then the next question was, well, would you rather be with a man? If the woman said yes, then the research result was, first of all, they said she was a lesbian because she fantasized about having sex with a woman, which is not what Kinsey would argue.

Secondly, they said she'd rather be with a man because she's only with a woman because she can't get a man. And you know, that's not a lesbian; that's a person who had a fantasy which, as Kinsey showed us, lots of people have lots of fantasies about lots of things. It isn't necessarily what they will do or what they would want to do or what they would keep doing given the opportunity. So there's a lot of bad information on disabled lesbians.

I jokingly like the "oh, wow" type of reaction I get when I go down the street holding another woman's hand in the U.S.--it's very common in Europe or Asia, but it's not common in the U.S.--and everybody just assumes she's taking care of me, which is sort of nice. It's playing on the myth that, first of all, women don't have sex together and, second of all, that able-bodied people or people who look able-bodied are definitely the helper and people with disabilities are definitely the helpee. Yet, you and I both know that when you examine those relationships, lots of lots of times the disabled person is actually the stronger partner.

I think that homophobia is a really big issue in the disability community. I think there are a lot of queers in the disability community, and it's not discussed, and it's not well known, and that's a problem. Any time you have people hiding, it's a problem.

Jacobson: Do you think that's true in the Bay Area?

O'Toole: Oh, yes.

Jacobson: And around the country?

O'Toole: Oh, sure. I mean, in the Bay Area you can have something like a disabled lesbian lunch--you know, Nancy Ferrerya used to have disabled lesbian lunches and forty women would show up. It's certainly much more acceptable in the Bay Area. I think it's partially because in the old days of CIL, there were lesbians and people were out about being queer, and so disabled lesbians were part of the community--much more so than gay men, but you certainly knew there were a lot of gay men, both disabled and non-disabled. I'm think about Ron Washington and oh, God, what's his--Scott Luebking, so there were always men and women who were gay and disabled and who were part of the local--certainly the East Bay, certainly the Berkeley disability community. I think that everybody who came through CIL got infused with the idea that it wasn't okay to be queer-bashing, that that was not an acceptable thing.

So that the problem I would hear other directors say about, "Well, I don't know what to do when they won't serve people with AIDS." We didn't have that problem in quite the same way. So I think it's better. But I think that when you don't provide services, when you don't provide information, it means that the people like me who can get the information anyway are okay, but the people who can't aren't. You know what I mean? The people just don't get what they need. And that's problematic.

Decision to Have a Child

Jacobson: Corbett, let's move onto another topic. Not too many years ago, you became a parent. And I know that you wanted to become a parent for a long time.

O'Toole: Yes.

Jacobson: Can you talk a bit about that process?

O'Toole: Sure. Well, one of the things that was significant in the early days of CIL was that there were parents: you know, Janice Kroner had kids and Judi Rogers had kids. I was looking at women with disabilities that had children and that were getting pregnant and having babies. When I knew Janice, I think her daughters were born, but I knew Judi during the period that she was pregnant. She had CP and she was walking. Then in the course of working there, I met a few other people.

I think I didn't really get it until Judy Dadak got pregnant. Judy Dadak, you know, is very, very short, like maybe not even four feet tall and has a very asymmetrical body --very weak-bodied. When she became pregnant and carried a baby to full term I realized, man! I mean, Judy became kind of my rallying cry--if Judy can do it, I can do it. Believe me, if her body could live through a pregnancy, I could live through a pregnancy.

So by the early eighties I had decided to just try and become pregnant. I wanted to use a known donor because I wanted my kid to be able to have a man in his or her life that was an identified man so when somebody said, "Where's my father?" you can say, "Oh, there's your father." So I found, actually, an older married couple that already had grown children and was interested in doing this with us. They sort of saw it as propagating--you know, making kind of honorary grandchildren if you will.

So I tried. We were using live sperm. I tried a number of times to get pregnant with them and was unable to. It turned out that the man had lymphoma cancer, which we didn't know at the time, but when we stopped inseminating about six months later he got diagnosed. And he was dead a year later. So what I now know about cancer is that when you have cancer in your body like that, it's trying to not let you reproduce because your body needs to use its energy for other things.

So then I waited for a few years--I had kids in my life and I would baby-sit and I would have kids around--then I decided that I would try again. In the late eighties, early nineties, I tried again. This time I used frozen sperm from a donor bank and again I didn't get pregnant. So by now, I was over forty and I thought, you know, I'm just not supposed to be a parent and that's the way it is.

Jacobson: I wanted to ask you, when you had to go out to a donor bank, how did people respond to you?

O'Toole: I actually didn't have much of an issue. I used a lesbian medical practice that pretty much the main thing they did was donor insemination, so I never actually talked to the donor bank people. These guys had their own donors that they had coordinated with. They had a book where you had to pick like whether they were a right-handed or left-handed guy, and what color hair they had, and what they liked to do. [laughter] It was kind of an interesting process.

Jacobson: Like a catalogue?

O'Toole: It was a catalogue. You didn't get a photograph, but you got a really good description. There were times you would pass the guys, actually, in the hall. Anyway, so that kind of issue--and also, the place that I was using was very inaccessible. It was up two flights of stairs. They were going to move, but they hadn't moved yet. I ended up having to do just one appointment there and then after that Jenny would just go and get the sperm. So I tried that.

I didn't get pregnant. And I thought, you know, I'm over forty, I guess I'm done with the pregnancy thing, and I guess I'm not supposed to have a kid. Because I had wanted to adopt and Jenny was like, no, no, no. She had already had foster kids. She thought it would be fun to have a birth child. She didn't want to get pregnant, which she gets pregnant, apparently, very easy, but she didn't want to get pregnant, so I was supposed to get pregnant.

But anyway, I didn't think about it anymore. I was sort of like, "Gee, it's too bad I didn't have kids in this life, I sort of thought I'd have a kid, but I guess I'm not going to have a kid." Then in October of 1993, Atsuko Kuwana and I were at a meeting and the meeting took a break and she turned to me and said, "Hey, Corbett, would you like a baby?" I was like, "Sure." And the whole room just went, "Ooeeh." I really meant it. You know, she had a letter from an adoption agency in Japan that said there was a baby girl with cerebral palsy available and would Atsuko and Michael, her husband, help the agency find a home for this baby.

Jacobson: This is Atsuko and Michael Winter?

O'Toole: Yes, well, Atsuko Kuwana and Michael Winter.

Jacobson: Michael Winter was the director at CIL at the time?

O'Toole: Right, and also they had adopted a child from this adoption agency in Japan two years earlier--a little boy named Taka Yoshi, who had a clubbed foot. Both Michael and Atsuko use wheelchairs and the adoption had gone very well. The social worker from Japan who brings babies to the United States periodically had seen them and had followed up with the family and knew that it had gone okay, so they felt--also Atsuko and Michael are very famous in Japan. There's a book that's been written about Atsuko's life and I think a film that got made. Michael lectures there regularly, so they were very high status people.

When I said yes, they called me the next day and asked, "Is it really still yes?" I said, "Yes," so they called Japan and said, "We found a family for you."

We found out fairly quickly that I had to present myself as a single person--this is again a lesbian issue; lesbians were not allowed to do adoptions internationally. It had never happened successfully, and in fact, in recent years, actually, the country of Brazil had shut down adoptions because two gay men from France had tried to adopt a child, so I had to go through the whole adoption process as a single woman.

Jacobson: So you had said yes right away.

O'Toole: Oh, yes.

Jacobson: You didn't go home and think about it?

O'Toole: No, I knew. It was clear. I sort of jokingly said later in an interview that I did, that when a god is sending a baby, you know, falling from the sky, you're just supposed to put out your hands and catch.

Jacobson: You were a lot braver about it than I was. I had to go home and think it over.

O'Toole: I see, well, I mean, I was forty-two, so ultimately I thought this was not going to happen twice--you know, I was an old woman.

Preparing for Meecha's Adoption

Jacobson: Okay. So you knew she was a disabled child?

O'Toole: Yes, I knew, at that point, she was a six-month-old baby girl with cerebral palsy. The social worker in Japan told Michael and Atsuko, "Well, it's very nice for you to tell me that she wants a baby, but you need to have her tell me she wants a baby." She said, "Have her write me a letter saying that she's interested in being an adoptive parent, and have her send me a resume." I did those two things. She looked at my resume and went, "Wow," and said, "Fine," and then asked me to work with the Bay Area Adoption Services which is a U.S.-based adoption agency that does international adoptions that this particular social worker and agency had worked with extensively. So even though I was living in Sonoma County at the time and Bay Area

Adoption Services was in Mountain View, I said sure. Because it made it easy since the two agencies knew each other and knew that the paperwork would be correct and there were no difficulties.

I did the paper work, the fingerprints, the home study, and all that. It was kind of interesting because the social worker would come to the house and Jenny's size ten shoes would be under the bed, and you know, I have like size three feet, so she would look at the shoes and look at me. [laughs] I figured she just assumed I had a boyfriend somewhere that I was stashing away. I was told by the adoption agency that because I was single, they would ask me if I was gay and if I said yes, they would write it down and it would go in the report. And if I said yes I would not get the child. I was told very directly, "You have to lie. If you don't lie, you will not get this child. I don't care how much they want to place this child and I don't care how much they like you, you will not get a child. They can not write on their forms we placed with a lesbian mother." So that's another way that the lesbian stuff kind of comes up interesting. So when she got to the question are you gay, I said no and that was the end of it.

In fact, it was a funny part because they have to do this whole screening about basically why aren't you married and who have you dated and so on. So when she got to that part about whether I was thinking about getting married, or was there a man in my life, I said, "Listen, I'm a forty-two year old fat woman in a wheelchair. What do you think my chances of getting married are?" [laughter] She kind of coughed and gasped--she was this hick social worker who didn't know anybody with a disability and in her mind my chances were zero. I had figured out by this point that was her attitude about me and about people with disability, so it worked very well. I, of course, had this great life with lots of sex, but she didn't know that --so I felt, "Fine," you know, "let her prejudice work on her own mind."

So, in the last week of January in 1994, I went to visit Japan with Jenny. And actually, it was very crazy because we flew from San Francisco to Vancouver, then Vancouver to Tokyo, and we arrived--and it was the year of international adoptions because, internationally, adoptions are not regulated in any way. There are no contracts, no written guarantees of any kind--not just if you don't get this child. In most countries, you're paying thousands and thousands of dollars in advance, and there's no guarantee that they will ever give you a child. There are more reputable and less reputable people, but even the more reputable people don't give you anything in writing,

so the U.N. had taken on the issue to try to discuss it worldwide. It wanted to try to convince the more reputable people that they needed to have a procedure in place that had some kind of agreement so people could separate the more reputable from the less reputable people, since they all look the same like in terms of lack of paperwork.

So I arrived at the airport to find a film crew waiting for me from NHK--from Japanese television, because they wanted to do a study on international adoptions. And I was the next international adoption at this agency and they thought it was interesting that a disabled person would want a disabled kid. So I rode backwards from Tokyo--from the airport into Tokyo--for about an hour and a half, and then went to my room, got to pee--

Jacobson: Why?

O'Toole: They wanted to film me. I was back-to-back with the driver in a van, so they could film me and interview me: "How are you feeling about going to pick up your baby?" I had been on a plane at this point for twenty hours, traveling for over a day. Then they're calling on their cell phones, "Get the baby ready, get the baby ready, we'll be at the hotel at seven-thirty." So even though I had been traveling--because I thought I'd get to sleep that night--no. They showed up, they brought the baby, I was in the hotel room maybe thirty minutes. I got to pee, that's about it, and they brought the baby to see me for the first time with the cameras rolling.

And I'm holding her on my lap, and I'm like playing goo-goo with her, and she's fine until she looks up and she sees my blue eyes. She's never seen blue eyes before, and I can feel her start to tense like she was going to cry, so I just turned her around so she looked at all these beautiful Japanese people. [laughter] I put one finger in her hand and she kind of squeezes my finger and they do a close-up of it, and they go, "Oh, this is so nice, they're bonding." She's like totally flipped out about my monstrous Caucasian face, you know.

Jacobson: How old was she?

O'Toole: At that point ten and a half months. And I didn't know what I was going to do about her name. I had thought I would give her an American name, because I've talked to a number of people that were Japanese American--Jenny's brother is married to a woman who's Japanese American, and whose family is immigrants, and they all got an American name and a Japanese name as part of her family--but she knew her name. Her name is Mitsuko--

M-I-T-S-U-K-O. And she knew it, and I didn't think she would. I thought living in an orphanage--but she knew her name, so I didn't want to change it.

In Japanese, Michan would be the nickname for a kid named Mitsuko. I knew that American--I had worked in childcare; I knew that the American childcare people could never do Michan, because so many people in the field are not native speakers--it just was forget it. So I just said, okay, if I made it American, what would it sound like? I wrote Michan and I figured that if people learned to read English as a second language, they learned it somewhat phonetically and it would go Mee-cha, so it's a nick-name variation on her original Japanese name. So her real name is Mitsuko, but her nickname is Meecha.

So we spent a week in Japan with a brand new baby--sleeping in a single bed with a little kid, I thought, "Oh, this is no big deal." Well, she'd been on her back for the entire ten months wrapped in swaddling--really wrapped very tightly on her back with her head just facing one way. The minute she was out of the tight blankets, the first thing she did was look like one of those frog images, you know, with her elbows to the side and her hands up by her head and her legs spread out; she took up half the bed in a single bed. And I'm not a small person, so sharing a bed with her was a little tough.

She didn't speak any language at that age and she didn't sit up or anything. She had never been up; she had only been laying in the bed for ten months. I was concerned that she was going to freak, not just about being with me and hearing English--and I knew like ten words of Japanese--but also about --you know, the film crew wanted us to go down to the restaurant, and they wanted us to go to a toy store. All I had was a fanny pack, so I just propped her in my lap and put a fanny pack around her and started pushing down the hall. She was thrilled. She was so happy to be out of that institution. She was so happy to be looking around the world: "Ooh, this is fun," or, "ooh, this is good, I like this." I was a happy mommy.

Jacobson: Maybe we can stop.

O'Toole: Okay.

Meecha's Adoption--1993

[Interview 6: November 4, 1998] ##

Jacobson: Let's talk a little bit about parenting and how it has affected you and what kinds of issues have come up with you as a disabled lesbian single adoptive mother.

O'Toole: You don't want much, do you? [laughter] Well, I became a mother when I was forty-two years old, in 1993. I think we talked last time about adopting Meecha, so I can skip that part.

Jacobson: Yes.

O'Toole: Okay. That's fine. And so at forty-two and a half I had a baby. Late January in '94, I went and picked up Meecha in Japan, in Tokyo. Jenny and I went and picked her up.

There are a lot of pieces to becoming a mother. One is that I really, really wanted to be a mother and so I was really, really happy to have a baby. I mean, it was really wonderful to have a child. You know, now, it's five years later, the adoption's going to be five years old in a couple of months, and I've had a really, really good time. [laughs] It's been wonderful. I've learned a lot, and I've had a lot of fun, and I'm really enjoying all the different ages that she has been so far. I'm enjoying how she learns and I'm enjoying kind of taking care of her and being responsible for her, so it's been really a wonderful--that part's been a really wonderful experience. There's been nothing in my life that's been quite so fulfilling. I have really never known love quite as unconditional as I've known with having a kid and having this particular kid.

So now, she's five and a half. So there have been a lot of different kinds of issues. One of the issues that came up during the adoption was the fact that Jenny was invisible. She was invisible throughout the adoption and, more importantly, she was invisible in Japan when we went to pick up the baby. She was in the lobby when Meecha came to the hotel and they wouldn't let--she couldn't touch the baby. She had to watch her go by her to come up to me because I was [quote] "the mother" and she was [quote] "nobody," and that was pretty stressful in our relationship. I mean, we both agreed to it, but it was very difficult, the intentional invisibility of her as a parent. That continued for the six months until the adoption was finalized. It actually took about ten months with

the paperwork and stuff, but until the adoption was finalized. There was this whole thing where every time the social worker was coming, Jenny had to leave the house. You know, we had to hide her stuff. It was this kind of insanity that didn't make sense.

Jacobson: How often did the social worker come?

O'Toole: Well, I had the world's laziest social worker, so--she had to do four interviews before the baby came home and she did I think two or three of them in my house because it was easier for her to come to me than it was for me to go to her. But that was for her convenience, not for my convenience.

Then the minute Meecha came home--which was crazy--here I was, I had no adaptive equipment, I was carrying my kid around in a fanny pack, I was in a push chair, I had this brand new baby who couldn't sit up, and I was schlepping to her office. She had gotten some job. I was schlepping to her office with this brand new baby in and out of a car. It was crazy. And I had to do, I think, four office visits with her. I don't know that she came to the house after Meecha arrived.

Anyway, the adoption agency I worked with I really liked a lot, but because they were based in Mountain View and I was living in Sonoma County, they just hired a contract worker that they didn't know very well and I didn't like very well. She did the social worker placement stuff, the paperwork.

But they did ask me during the adoption process if I was a lesbian and I was told that they would ask me that and I was told that I had to say no. So it was--I haven't been in the closet about my lesbianism for years. I mean, I came out in 1974, so it was pretty shocking like to be a lesbian for eighteen or nineteen years or twenty years and suddenly I'm like lying to people about whether or not I'm a lesbian.

What I did get, though, with the adoption of Meecha, I immediately belonged to four completely different and pretty much mutually exclusive parenting groups. I was a lesbian mother, so I was part of that community. I was a mother with a disability, so I was part of that community. I was a mother of a disabled child, so I was part of that community. And we were an interracial family, so I immediately realized there were four completely distinct communities that I actually needed information and support from.

I discovered very, very quickly that none of them talk to each other. And you know, on a really, really lucky day I

would find someone--another family--that was in two of my four categories, but I pretty much almost never find people that are in all four and almost never find people that are in three or four. Once in a great while, but it's pretty rare.

In terms of challenges, although there are a lot of different kinds of challenges that happened for us as a family --I mean, being lesbian mothers in Sonoma County that was a multiracial family was pretty challenging. I would go to the grocery store and I'm this very white, pale-skinned woman, and I have this clearly Asian baby on my lap, carrying her around the grocery store. People couldn't figure it out because in Sonoma County there was often an assumption that white people were like babysitters for Asian children and not parents of Asian children. But then I didn't really fit the kind of stereotypical babysitter mode either because I was in a chair.

And I actually have the experience of going to a disability appointment for California Children's Service for an in-take evaluation and the social workers and the doctors during my in-take interview, asked me questions like how much did you pay for her and from what country. They would say things like, not politely, what country is she from, but, "Korea?" I'm like, "Excuse me." Yes, so there was a fair amount of pretty significant racism going on and prying into my personal life about her adoption.

I made a decision during the adoption to keep some facts of Meecha's adoption private. I got that from meeting other parenting groups--information about her birth family that I know that Meecha will know, but that I didn't put out in the community. Other than the fact that her birth mother really fought very hard to keep her out of an institution when the orphanage couldn't place her--they tried to put her in an institution--other than that I pretty much don't disclose much about her birth family and let that be Meecha's private information. I got that out of being in an adoptive family support group. So there's actually that fifth category, you know, just being an adoptive family. So actually I'm in five support groups. [laughs]

Disabled Mother-Disabled Child Challenges

O'Toole: In terms of other kinds of challenges, you know, I was forty-two years old when I adopted my kid. I was not in my physical prime. In fact, my polio had been getting worse for a period

of about twelve years. I started getting significantly worse about thirty and I've been kind of going downhill since then. I under-appreciated how physically exhausting it was going to be to have a child. I really did not in any way anticipate or expect or plan for how physically difficult it was going to be to have a child. I hadn't really built in any--I hadn't used attendants, so I hadn't really built any kind of that support system. And it became pretty clear to me in Sonoma County that I wasn't going to be able to make it alone as a parent. Jenny was going to school at the time--Jenny was going to be working outside the home, I wasn't going to be working outside the home except for traveling. It became pretty clear to me that I was going to need more physical help.

Very soon after we got Meecha, we both decided that we were moving back to the Bay Area, we were moving back into the Berkeley-Oakland-Emeryville-El Cerrito-Albany area where we knew a lot of people, where there were a lot of families that looked like us in some configuration or another. You know, either they were multiracial families, or they were parents with disabilities, or they were parents with disabled kids who had some political awareness about disability. Because when I was in Sonoma County, I was going to these parent groups where people were just crying about how tragic it was that disability had entered their lives and it wasn't exactly a particularly supportive environment for me as a person with a disability who's also a parent.

There was also the challenge of having a disabled kid. I really forgot how much energy I had about my disability and my childhood and about things that were done to me, like surgeries that I really didn't approve of or want. I didn't anticipate how difficult it was going to be. Although many, many years earlier, when I was at CIL many years ago, there was a woman with MS named Pat Bentley who had a kid and we were talking one day and I was saying, "Oh, I always wanted to have kids and I'd love to adopt." And she told me, "Don't adopt a kid with a similar disability because then your issues and their issues are going to get stuck together." She was really right. [laughs] You know, if I was picking maybe a different kind of category of disability--but here I am sitting in rooms with physical therapists, with occupational therapists, with orthopedic surgeons, having the same discussions about my daughter that my mother and my father had had about me at the same age. And they made decisions that I wish now they hadn't made.

So it's been very hard to figure out how to manage what Meecha needs for her body and her life and separate that from

what was done to me, in terms of what decisions people made. All the disabled adults I know talk about the bad decisions that were made for them. It's difficult to figure all that out. The positive side has been that when I sit down, whether it's for an individualized education plan at an IEP, or any meeting with professionals about Meecha, I am a total peer. I have no assumption of inferiority or lack of knowledge about the situation, which is a common situation for parents, that the professionals are talking over your head. I sit at the table and just say, "No, this is my kid. Physical disability is an area where I have a lot of personal experience, and I know a lot of people with her disability." I used the community as a resource, like when she didn't want to toilet train. Did I tell you that already?

She didn't want to toilet train at all. She was three, then three and a half, and then she was four, and I was getting really cranky about it. And I couldn't figure out why--I couldn't figure out whether she was stubborn, I couldn't figure out whether she had bladder control, whatever, so I just stopped every woman who was a spastic CP for a period of about four months and asked, "Are you spastic?" And if they said, "Yes, why?" I said, "Well, I have this kid and she's spastic CP and I'm trying to figure out about--we're trying to toilet train her and she doesn't want to toilet train, and I'm trying to figure out why. Can you tell me about your bladder? You know, how does it work? What's easy for you and what's hard for you?"

People were really great, once I explained it. Basically they said that they could hold it all day and that they didn't have to--bowel or bladder control wasn't really a problem unless they were really laughing hard and then sometimes they peed in their pants, or sometimes if they had a full bladder and they were startled pretty big, there might be a little leak. But in general, they had pretty good bladder control.

So I then knew that that was a realistic expectation for Meecha to develop bladder control and that there were just typical kid issues about why she did or didn't want to pee. And it turned out a lot of it was the hassle of having to ask for help and having to know that you had to pee ten minutes before you have to pee because you can't just run in there by yourself and do it.

Jacobson: And then there are people waiting around while you're trying to pee making it more difficult because your bladder muscles tense up--

O'Toole: [laughter] Right. Like my daughter never had the experience of peeing in private.

Jacobson: I can tell you.

O'Toole: Okay, I'll read your oral history. [laughter] So there were those kind of issues about me coming into the scene. I think it's a benefit to have friends of mine like Linda Gardner who has a daughter with cerebral palsy who is three years older than Meecha, so when Meecha's five, Alva's eight. Their birthdays are like close together. Linda's a county administrator, so she can certainly hold her own with other able-bodied people, but she said that it's a completely different atmosphere in a room when I'm there--when a disabled adult is there talking about disability--than when it's all able-bodied people talking about a disabled child. So I think that that's been an asset for both Meecha and me. I get to think about issues that I thought I never was going to have to think about again, and she gets the benefit of my community experience. Because that's how I see it; it's not just about my experience with polio--I don't have CP, you know--it's about her community of people that she can rely on and get information from.

It also meant that I was fairly sophisticated in a non-typically parent way about equipment and resources. For example, I knew when she was three and not standing, much less walking, that we had to start thinking about wheelchairs. Actually, I started at two to think that she might need a power chair. I knew that our health insurance would only pay for one thing every five years, so I saved that chip, the power chair chip. I didn't want to use it until she was closer to four, so when she was two and not walking and I needed a manual chair that worked for her in a preschool environment--at that time there were none that existed that were affordable or available --I went to Ralf Hotchkiss who builds chairs and the Whirlwind Mobility People. I said, "I need a wheelchair and you guys owe me favors, so, please help me out." Ralf and I designed--with some therapists. Then Jan Sing built a frame for Meecha and then Judi Rogers and I did the seating, and so basically the community built Meecha a wheelchair from scratch that was appropriate for a preschool environment.

So it was my ability to know what her needs were, anticipate them before they really came up, my pushing the whole system--because one of the things that happened early on with her IEP, in a first IEP, is I said to the director of special ed, "I want my kid to be a kid (a) that does not have an aide in the classroom and (b) is a kid that in five years

you don't even know she's in the school district." The head of special ed turned to me and said that, "No parent has ever said that to me. Usually the parents are coming in, especially when the kids are young, begging for one-to-one everything." I was like, "No, my kid's like me, you know, like my friends. She's going to live an independent life."

And they couldn't get it. People kept trying to give me to aides and they couldn't get it, and I just had to keep saying to them, "Listen, I am not Rockefeller. We are not rich. She will not have one-to-one help as an adult; she has got to learn now at two and three and four and five how to manage in the world of able-bodied people, where she's going to be without one-to-one help. She needs to figure out and learn those tools now because that's how she's going to go to school, and that's how she's going to live her life, and that's how her life's going to be like at home. She needs to learn those skills and that's an important part of her education. If she doesn't learn now, then she's going to have a terrible life as an adult and that's my job as a parent."

Jacobson: It's interesting to hear you say that because that's the way you and I, and a lot of people we know, grew up--with the real push to be independent, to do as much as we could by ourselves. Now, parents seem to have a different attitude that's almost the opposite of how we grew up. What do you think happened to cause that shift?

O'Toole: I'm missing the point. I understood all the words, but I'm missing the point. Are you saying that we were pushed to be independent and that kids today aren't?

Jacobson: Or that's what it seems like.

O'Toole: Well, I think that what happened was that, certainly when we were growing up, the push was to put all the disabled kids in one class or one school and ship them wherever that class or school happened to be.

Jacobson: Right.

O'Toole: When classroom teachers or administrators say to me, "We need to give Meecha an aide," what they're saying to me is not that Meecha needs an aide, what they're saying to me is, it is our administrative convenience to isolate your kid with one person and take the concept of a separate class and sort of integrate it into a regular classroom. What I showed them and what I knew about my kid, just from a pure personality point of view, is that my kid, just like most kids, if you give them a one-to-

one grown-up, they're just going to be like princesses. They're just going to sit back and go, "Fine, I'm a little princess," and you know, "Do it for me."

I had to go through the experience with a regular teacher--Meecha had an aide for a while, but everybody got to see that what was happening was that the parents were thinking that Meecha couldn't play with their kids without an aide there. The classroom teachers were doing things like every time Meecha had to pee, they would yell, "Aide, Aide," you know, across the classroom, so everybody kind of saw what happened. Then the aide got another job, and the regular classroom teacher said, "Well, we'll struggle through until they hire somebody else." They realized that Meecha became a much more independent kid without the aide than with the aide, which I had been saying all along, so they got rid of the aide.

One of the things I fought for Meecha was to have the whole team of us--because it's like twelve people that Meecha sees on a regular basis--the whole team of us meets every six weeks during the school year. It's not mandated, it's not legally required, but in a small school district, people want to communicate. So the classroom teachers, the physical therapist, the occupational therapist, the aquatics physical therapist, the computer specialist, the head of special ed, me, the speech person, all sit down every six weeks and just talk about Meecha. So everybody got the feedback that Meecha was looking better without an aide than with an aide.

Jacobson: It must take a lot of effort on your part.

O'Toole: Oh, yes. It's a job. I mean, parenting a severely physically disabled kid, which is what she is, she's a spastic quadriplegic, she's five and a half years old, she does not walk, she does not transfer by herself, she has no--she's just now developing some independent mobility indoors. I mean, she could always crawl around, but she can like push around in a wheelchair and reach things and carry things, but that's been in the last six to eight months. She can pull herself to a standing transfer, but she can't make the transfer. You know, she's just in the last three months learned to undress herself, so she's a pretty significantly disabled kid for her age.

Over time, it's going to even out and she's going to be less disabled because her strengths now are not things that are really age four or age five skills, which is being able to sleep well, being able to think well, being able to use a computer. But by the time she's ten, she's going to look less disabled than she looks at five, even though her actual

mobility is probably not going to change very significantly. Her ability to adapt to her environment and the skills that she has are going to be more useful to her then. But yes, it's a part-time job. Between managing the therapists, getting the braces, taking her to appointments, [sighs] you know, checking on her stuff, going to these meetings, really it's a one-third to half-time job on a weekly basis all year round. In the summer when the therapists aren't there, more of the responsibility about what isn't being done falls to me.

I wanted just to say that one of the places that was the most important place for me to get support early on--it's a two-parter. Two things I needed early on was I needed physical equipment: I needed a way to move my kid around, a way to bathe her. I was having some pretty significant concerns about safety with her when she was a baby, because first of all she was floppy and second of all there was a ton of stuff that was really hard for me to do. I had a Volvo station wagon, so transferring into a regular car seat was really difficult. I could get the lift, but as soon as I leaned forward I would sort of lose my balance and so her head was smashing against the car seat all the time. I couldn't bathe her safely and I couldn't carry her very well, so I went to Through the Looking Glass or Judi came to me--actually, we realized--there's a video of Meecha like six days after she arrived in the States, Judi and Megan came by and did a--

Jacobson: Judi Rogers?

O'Toole: Judi Rogers and Megan Kirshbaum from Through the Looking Glass in Berkeley came by early on and did an in-take evaluation and videotaped her and videotaped me with her and then gave us some equipment. They gave us--I think Judi calls it a front pack, an adaptive way of carrying Meecha, so that my hands were free to push my manual wheelchair.

They put a baby's bathtub on a typing table with some adaptations so I could fill it and move it around as I needed to. So basically I could give her bath in any room and open and close it and fill it with water and empty it pretty easily. And my friends pitched in and got me a car seat that turns 360 degrees so that I could do--instead of just facing towards the driving wheel, it would face actually the opening. You could turn it and it would face towards the open door, so that was something that really made a difference.

The other thing that made a difference in the community was that Meecha's birthday was in March, so she arrived in the states like February 2, and people threw her a birthday party.

The community had a big old welcome to our disability community. Like fifty people showed up to say basically to this kid--I mean, she doesn't remember any of it--welcome. And I think that was a pretty significant statement, and that pretty much continued.

I think that so few of us have kids in the disability community that to a large extent a lot of people see our kids as part of the community. Particularly because she's physically disabled and I'm hanging out mostly in the physical disability community, people have really taken her on as like one of the kids, as if we actually birthed this little crippled girl and she's one of our kids.

The second place that I really needed support was I was pretty freaked out I was going to drop my kid. And I didn't want to tell anybody. I certainly didn't want to tell the able-bodied social worker from the adoption agency. I couldn't talk about it at the parents group where the kids were disabled, because I was terrified somebody was going to report me to child protective services [CPS]. Now she's five and a half and I haven't dropped her yet, but certainly when she was a baby, I was terrified that I was doing transfers that were pretty kinky, you know, pretty unsafe, and doing my best, but a lot of stuff wasn't safe.

I was really worried about it and I started going to the parents with disabilities support group that Through the Looking Glass runs once a month and that Judi facilitates. Actually early on Hal Kirshbaum--who could still get out of the house at that point--came to the group and talked about all the research on all the parents with disabilities, saying that parents with disabilities worry about that safety issue much more with their children than parents without disabilities. Yet the actual rate of dropping or falling is not any really different.

But the parents with disabilities worry about it more because we just we worry about it more. And we worry that there's going to be bigger consequences if it happens and somebody sees it, whereas, my able-bodied sister and her kids, they've probably fallen off the couch ten times and nobody was going to ever call CPS on her. But if my kid fell off the couch once, I was terrified that they were going to call CPS on me. So that was an important place to get support and to really think about what it meant for me to be a disabled woman having a child, how to adapt my environment, and also how to adapt my way of thinking about raising a kid: what was I going to be able to do and what was she going to be able to do.

And some things in our lives are certainly--like when she's home, she's on her own for mobility. If she wants to be in her chair she can be in her chair. If she wants to be on the floor, she can be on the floor, but I do not do any extra transfers for her at all. I mean, other than getting her in and out of her wheelchair or on and off the toilet--the toilet, the toilet I'll do as often as possible--but the wheelchair I do as infrequently as possible. She comes home in her wheelchair and she says, "I want to play and I want to eat and I want to do this and do that," so I try to do all the wheelchair stuff at the same time and then all the floor stuff at the same time. Because I'm not going to lift her in and out of her chair eight times.

Jacobson: Yes.

O'Toole: I put her bed as a mattress on the floor so she can get in and out of her bed all by herself. So I do a lot of things that are for me and for my disability regardless of whether or not they're optimal for her disability. But a beneficial side effect of my not lifting her so often is that she either pushes or crawls when she's home a lot more than she might be at school. In school where there are other kids and the space is pretty small, people would probably push her around and she's rarely on the floor. And she likes that, but I don't do it for the PT [physical therapy], I do it because I don't want to lift her ten times in a day.

The issue about being a lesbian mom is a much trickier one. I mean, one of the things that happens in special ed is that almost all the professionals I deal with in general are white. It's not that common for there to be a lot of people of color making decisions in special education: neither as therapists, or as classroom teachers, or as directors of special education. And everybody looks straight, whether or not they are straight, so it's a system as a whole that doesn't have a lot of room for diversity. I'm always in rooms with basically able-bodied white people who think they know about disability. But they don't know about disability the way I know disability, they don't know about multiracial families, they don't know about lesbian issues--and so there's a lot of cultural invisibility in terms of my family and how it exists.

One of the reasons I've put Meecha in center-based care versus family-based care is that it offers her more support, more staffing, so that her disability is more easily accommodated.

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Jacobson: You talked a little about being involved with agencies--as a client and as a leader. Can you talk about some of those experiences you've had with Regional Center and FRN [Family Resource Network]?

O'Toole: Oh God, Regional Center. Well, I have to honestly say that, for me, I do much better in systems where the people on the service delivery end of the system have some direct experience with whatever I need. So, when I was at Through the Looking Glass and there were people there that had personal experience being parents with disabled kids, or being disabled parents with kids, it made a difference. When I go to Regional Center, and I'm on like my fifth social worker--they go through social workers like water there--pretty much my experience has been that it's a system that is not set up in any way, shape, or form for me or my daughter: it doesn't respond to or really listen to our needs very well.

I jokingly say that Meecha's the equivalent of a paraplegic and I'm the equivalent of a paraplegic, and together, as a family unit, as a parent-child, we're like a quad and we need to be thought of as a quadriplegic in terms of the services that happen. Yet, those systems were all set up assuming that --like Regional Center, like California Children's Services--there's an able-bodied parent who's willing to basically break their back lifting, schlepping and carrying their kid, and so the need for adaptations in the home or the need for adaptations in the environment doesn't exist. So my kid needed a standing walker, a standing frame, for a year and a half and we can't get one because none of the systems look at our family and think about (a) what does the kid need, and (b) what do I need, and how together--because they're assuming that there's one or two able-bodied people to hold the kid's hand on either side and help the kid stand or walk. That's not something I can do. They assume there's somebody there that can put her on all fours and help her to crawl across the room. That's not something I can do.

So systems like Regional Center and California Children's Services and Kaiser Permanente medical system, which is my health insurer, don't have any clue. I mean, they see each one of us as a totally separate individual and the interaction of the two of us which significantly increases the level of both of our disabilities doesn't get factored in at all.

In fact, what's happened to me physically is I've actually gotten much worse. I have my kid in full-time day care, full-time child care, because she's an only child. And, as I jokingly, but honestly, say to her, because she's always going

to be an only child, I want her to have a lot of social interaction with her peer groups because she needs that experience and exposure. She came from another culture, from another country, she needs to get Americanized in terms of functioning, and the social mores and stuff, but at the same time, she also needs to be in child care because I can't do full-time care of her. And last year when she was home for two weeks over Christmas break my back was out for about three months after she went back to school. So those kinds of things just don't get factored in.

When I call people like the Family Resource Center, I have a completely different set of experiences because the people on the other end of that phone, the people I'm calling, every single one of them is a parent with a disabled kid. Now, their kids could be totally different than my kid and I could be talking to a woman whose kid had Down's Syndrome, or talking to a woman whose kid has encephalitis or whatever. But their child's type of disability is irrelevant because what they know is they knew the experience of being in systems that are not responsive to our needs as parents, and not responsive to our children's needs.

They are also people that are sitting there having to have these horrible discussions with these horrible professionals about whether or not to cut open your kid or whether or not to put your kid on drugs, or whatever, basically knowing there's no guarantee of anything--it's just a crap-shoot. I think that that's a pretty significant challenge that parents of disabled kids have to face, is what to do, knowing that there really is no right answer. You don't really know what the outcomes are going to be and you just have to decide how much time and effort you need to put in and how much invasion you want to do on your kid's life to make some hard decisions. So for me, having people on the other end of the phone that reflect back my experience in whatever ways, even if it's only one of my five categories--even if they're heterosexual, white, monocultural families [laughs], straight--but that they had experience with being involved with the disability system as parents of disabled children, we're fine. I don't know if that's the kind of story that you wanted.

A Different Childhood

Jacobson: Corbett, how are Meecha's experiences as a disabled kid different from yours when you were growing up?

O'Toole: Well, there's sort of a three-tiered part to that: one is that when I was growing up which was in the fifties and early sixties is one time frame, and then I became friends with people like Jackie Brand who were raising their physically disabled kids with CP in the seventies and eighties, and then there's the Meecha time. What's striking to me is how similar the experiences are between those, if you will, three generations: me; Judith Brand, who's now twenty-four; and Meecha, who's five. The public schools still think disabled kids belong someplace else--anyplace else other than the regular classroom; services for disabled people are still very fragmented and very medical oriented; it's still about physical therapy, it's not about playground access or whatever. What I see that hasn't changed is this assumption that disabled people are different and separate and belong someplace else. And parents, whether it's my mother or whether it's Jackie Brand or whether it's me as Meecha's mother, have to fight against that all the time to even get the most basic level of a life for our kids. So I think that that's what hasn't changed.

I think what has changed a lot, particularly in this group in the Berkeley area, is the understanding that kids with disabilities are going to grow up to be adults with disabilities, who are going to go out in the community and live a life.

One of the lessons that I learned that was the most striking for me--when I was a teenager, I volunteered at a local community center that had a program for retarded adults after school and on Saturdays, and I used to go and volunteer on Saturday. I realized pretty much that most of people I had dealt with had been socialized, which I didn't realize at the time--I was fifteen years old--and were functioning at a younger age than I was. Not in terms of reading and writing--although that was certainly true, they didn't read or write--but socially and emotionally. They didn't walk to the store by themselves; they didn't do things by themselves that I did at five and six and seven years old. The whole expectation was that it was totally appropriate for fifteen-year-olds to be telling them what to do and planning their activities and running their lives even though they ranged in age from twenty to fifty.

I moved to Berkeley and met people like Barbara Lubin and her son. She had a child with Down's Syndrome, who could read, who could read and write at eight years old, and it blew my mind. It made me realize that it wasn't about--it was about our assumptions. I had gone to school to be a special education teacher for the retarded assuming that we were just

going to put them in the same classroom and teach them the same curriculum year after year after year--never expecting them to learn it--and created the kinds of adults I was working with when I was fifteen years old. When Barbara Lubin came and had Charlie and said, "No, this is a kid that's going to be part of the community because there are other retarded adults that are part of the community," everything changed for me.

I mean, it was a very transformative time for me, also, living in Berkeley and seeing people with severe disabilities. People that I had seen living in state hospitals when I was in Massachusetts were people that were out in the community. And in fact, in the case of Hale Zukas, were actually running things. I had to go to him to say, you know, "What's the situation with transportation, and what's the situation with the law?" That was unthinkable to me when I was younger.

So for me, it taught me two things. It taught me, one, that I have to be vigilant about Meecha when she's younger, to not do interventions with her, to not allow the system to assume she's less because she will grow into their expectations. Twenty years from now we'll think about CP kids completely differently than we think about them today and the interventions will be completely different. I need to kind of help her wait for the better interventions and not let the worse interventions get in her way. I need to keep looking at the long picture. My friend Linda Gardner says that the thing that I've given her the most is the idea that--she's always planned ahead for her daughter Alva, who's eight and has cerebral palsy, but only a year or two ahead--she's now looking ahead, not at ten but at twenty years. I'm helping Linda look at what kinds of skills Alva is going to need at twenty, because they're essentially the same as ten, but it's societally not as acceptable to push for them at ten. I think that that's a difference.

The other thing I think for Meecha is she's growing up in a community where she knows tons of people with tons of disabilities who are doing everything. You know, Mary Duffy's taking off her clothes and doing performance art with no arms. Her aunt and uncle, Pat Chadwick and Steve Dias, are adopting a baby with one arm and one leg. Ralf made her wheelchair. I mean, and you guys [Denise and Neil Jacobson having CP and raising son David]. I mean, she just knows so many people with her disability, with different disabilities, who are doing stuff.

I think that that's what's significantly different for Meecha, because I didn't know anybody with any disability when

I was a kid. What's significantly different for Meecha is that she believes that the world is a wide-open place; that disabled people travel, disabled people have children, disabled people run businesses, disabled people go to work, disabled people get sick and die. I mean, the whole range of life is available to people with disabilities and it's not about--she doesn't have to guess it. Even though books at school don't really reflect it very much and even though her teachers don't reflect it in the classroom or the culture, she knows. The other half of her life that's outside the classroom when we travel--I take her with me on my work--where she sees the world, where she meets people from other cultures, and I think that that's a significant--probably the most significant difference--between how I was raised and how she's being raised. I was raised very much in isolation with my disability.

Jacobson: Do you think she is still experiencing discrimination?

O'Toole: Oh, yes. Well, we just had a talk about it at her team meeting last week about kids that don't want to play with her. You know the hardest part for me about parenting is I'm waiting for the other shoe to drop. I know she's disabled, and I sometimes will watch her classroom environment and see stuff happening, but she doesn't get it yet. Yet when I talk to all the--it's like kindergarten, first grade is when you sort of get the clue about how really different you really are--about both your family is different races--your mom doesn't look like you--or about your disability stuff.

She had an experience last week where kids weren't playing with her and she went to the teacher and said, "The kids won't play with me." And the teacher said, "Well, go ask." You know, "Who would you like to go play with?" "Alexis." "Well, go ask Alexis." And Alexis said no. In that moment, the different kids didn't want to play with her because the activities she could do were not activities that they wanted to do at that time. So there's stuff where there's social--not just differences, but also there's--I don't know how do you describe preschool discrimination, but that's what it felt like. I mean, her experience of it was no different than if I went to a shopkeeper who didn't want to wait on me.

Meecha's experience of it was in the same realm, even though in the bigger picture you can just say, "Well, that's just a preference at that moment in time with that child." Or, is it just the preference of the shopkeeper to not want to wait on me or let seventeen people go ahead of me because they don't feel like hassling with whatever I need? It felt the same, and it felt the same to the teacher. They actually brought it up.

I didn't bring it up, they brought it up to the team meeting that they were concerned about it.

We talked about helping Meecha sort out being able to ask for an adaptation she needs versus being bossy just for the sake of being--sometimes what she'll do is just order the kids around, which they don't like either--and helping her understand about how to separate asking for something. Like if she says, "I can't play with that toy if you put it over here, I can only play with it if you put it on the table," which is asking for what she wants versus bossing the kid and saying, "Put it on the table." The kid doesn't know whether that's just because that's the way Meecha wants it because of her will or because she needs it because of her disability and sort of helping Meecha to make those distinctions.

Jacobson: Do you think that every activity can be adapted?

O'Toole: That's such a funny question--I mean, not a funny question--but such a hard question because I have seen it so much based on the teachers. If the teacher has a world view that all the kids in a particular group belong and should be doing a particular activity, then those teachers find ways of making the activity easy for all the kids. I'm thinking here of like a P.E. teacher one time that did "Red light, green light" where everybody crawled and so it was a game where Meecha was a total equal.

But if the teacher's perspective is that "Red light, green light" is a game that everybody plays standing up, and Meecha plays in a push chair where she's not at all competitive with kids that are walking--when it's about getting to the end of the line fast enough--then no. So it's not really that I don't think that everything can't be adapted, I think it's a matter of perspective. When you're teaching or when you're a parent--who do you want--I feel people make decisions about who they think belongs doing that activity and then they--so if "Red light, green light" is only a stand-up game and that's the teacher's perspective, then Meecha will never be included. And then fighting with that teacher to quote adapt it, like giving her a head start, is kind of--it's an okay intervention, but it's not really the point. The point really is if Meecha's part of a group that wants to play "Red light, green light", how can that group play "Red light, green light" together? If she's not part of that group then it doesn't matter whether or not it's adapted because she's not part of that group that wants to play it, anyway.

So I don't know if that really answers your question. I mean, I think that I want physical environments to be

accessible--playgrounds and classrooms and bathrooms and tables and sinks--but I think that the activity adaptation, the activity access, is so much more about people's individual perspectives about who belongs and who doesn't. My experience with disability, which started with the KIDS Project, is really just that people have different world views. They see the world as if they have a five-inch, or a ten-inch, or a 100-inch world view; their vision, their blinders, if you will, make them see different things. People that have pretty open, pretty wide world views of who can be in a community tend to do better with disability--people with disabilities--than people that have more narrow world views of how things should be done.

Jacobson: I think that's a very good way to put it.

O'Toole: There's a woman that teaches at Bananas (a childcare resource and referral agency) who's a childcare provider--did I tell you this already?

Jacobson: No.

O'Toole: Who says that her grandma taught her to be a childcare provider. Her grandma, her mother, and she are all childcare providers. They all run a family day care. She says what her grandma taught her about kids is that--about people--is that we're all flowers in God's garden, and that if you think of the world that way, then it's just a matter of just a different kind of flower. It may be one that you've seen before and it may not be, but basically about everybody belongs. And this puts it in a context where people don't get hung up with labels. If you only want cactus gardens, or you only want manicured rose gardens, then you're not going to do well with all flowers. I think that for me, that's been a helpful training perspective of working with people about attitudes.

Jacobson: Is there anything we didn't cover about parenting?

O'Toole: I think that it was surprisingly stressful on my relationship. I really underanticipated about going from two people in a family to three people in a family. The primacy of the two adults gets shifted and suddenly there's a third--it becomes a triangle. I think that I really underanticipated how stressful that shift was going to be. In some ways it opened up the relationship between me and Jennifer to kind of have some space, but in another way it actually demanded a lot more of us physically. Because Jenny's back went out not too long after Meecha came and Jenny was in bed for six months, and Meecha wasn't walking and Jenny wasn't walking, so I was doing lifting--kind of helping physically with both of them. So I

think that part of parenting was the part that I most underanticipated.

I think that Jenny and I were headed towards breaking up before Meecha came, I mean, in the long-term picture. We had kind of been growing apart for years and we were headed that way anyway, and to some extent Meecha kept us together for a period of years. Jenny wanted to make sure that I had the financial support and the resources and the emotional support that I needed to be able to make--especially the early years, to do the early years of Meecha. Once it became clear that Meecha was pretty stable healthwise and schoolwise and housing was set, then Jenny and I were both more free to go back to where we had started before Meecha arrived and pick up basically moving away from each other.

Having a disabled kid has taught me a lot of resilience. It's taught me a lot of dealing with the unexpected. My cousin told me--before I had a kid, she said, "You know, you'll never again be able to make a plan and know you'll be able to keep it," and she's right. I think I've got a date, I think I'm going to the movies--maybe not. [laughter] Meecha could get sick, you know, stuff changes, so I feel like that's a pretty big difference.

Jacobson: I know that before I became a mother if anybody ever tried to tell me what it would be like, I would have never believed them. But now that I am a mother, it's mind-boggling. It's a twenty-four-hour-a-day job--

O'Toole: Forever.

Jacobson: Forever. You never stop caring or worrying. They keep testing you. How does Meecha test you?

O'Toole: Well, as Judi Rogers told me when Meecha was like ten months old, "You know, she has a will of iron," so she does a fair amount of ignoring me when I ask her to do things, especially like when we're in a rush. That's a pretty good way to test me. Negotiating with me about things--you know, that's the worst of my habits, kind of having a battle of wits with me, not battle of wits, but a battle of wills, with me about stuff. Yes, I mean, for me, she's not yet at an age where she's emotionally very draining. Every once in a great while, she'll just really piss me off, but it probably happens five times a year. But really for the most part, she's pretty mellow and I'm pretty mellow and we mostly get through it. A few times a year I just have to say to her, "I'm going in the other room, I've had it and I'm just really upset," and then I come back

and deal with whatever it was later. She's at that age where she wants to tease you and make you crazy, but then if you laugh about it, it goes away.

I had terrible teenage years--I had a horrible time, and I'm really dreading the teenage years of my kid. So I'm working really, really hard to enjoy the age I've got and trying to be really flexible now because I know that I'm not good with that mouthy difficult stuff where they know more than you do. I'm dreading it.

Jacobson: How did your family react to the adoption?

O'Toole: Well, I would say that pretty much all of the people of my parents' generation--both Jenny's parents--well, Jenny's mother was alive, her father was already dead when I--no, actually, both of her parents were dead when we found out about Meecha. That generation thought we were crazy, because they really knew what we were getting into. They really and truly understood what it meant for a family to take on the responsibility of a significantly disabled child. They could anticipate what it was like for able-bodied people to do it, so they just extrapolated to me. So everybody pretty much thought I was nuts. I just bravadoed my way through it: "Oh, it'll be no big deal." But what do I know: "It'll be no big deal and there's nothing to worry about," and, "You know, I've gotten into worse situations than this before," and they knew I didn't know. But I would say that my family's pretty much taken in Meecha. And we just did a trip back East to visit family and, you know, everybody was giving her presents.

I mean, yes, there's a fair amount of--one of my cousins that I'm fairly close to adopted a child from Korea a number of years ago, a baby from Korea, so there's another Asian adopted child in the immediate family. So that issue wasn't--my cousin took a lot of hits for that in terms of the race stuff, but I haven't really had to deal with that very much.

I also live out here, which is a better place. You know, that's part of why I live here is because of the diversity. Meecha's never in a school--the other thing I want to say about center-based care--Meecha's always in a school where there are other gay families, other interracial families, other children with disabilities, so that there's never like--like right now there's a deaf kid in her class. She's never in complete isolation, it's not as inclusive as the world that she and I live in socially, but it's a lot better than it would have been, for instance, in Sonoma County.

IX CURRENT ACTIVITIES AND REFLECTIONS

Direction of Disabled Women's Rights Movement

Jacobson: Okay. I want to switch gears and to go back to the kind of work that you do in the women's movement. What are your vision and your view of where the disabled women's rights movement is going?

O'Toole: Okay. You know the saying--the old curse to live in interesting times. I think that the twenty-five years I've been doing women in disability work, it's been interesting. It's been really slow and really painful--how really slow and painful it is--but it's been interesting work. I think that from here, I feel more secure for the first time in about ten years that we're actually doing our job as disabled women leaders of reaching out to younger women and bringing younger women into the movement and making that part of the movement more solid. We're doing a better job of doing that across racial lines and to some extent internationally. I feel like I now know a whole community of women in their twenties or young thirties who see themselves as disabled women leaders, who are running programs and who are focussed on women in disability work in some significant way. That's a big shift.

I feel very, very hopeful that the work around women in disability will continue. I feel like the person-to-person networking around women in disability has gotten much stronger. It started to happen at Beijing, and the SDS conferences, the pre-SDS conferences, and it happened at the big Bethesda Conference last year [1997]. It's happening with Mobility International having women's leadership conferences.

The individual networks are getting really strengthened, but what's not happening very effectively, in my opinion, is the development of any organizational infrastructure. I think that's a significant problem, that when I talk to women around

the world, it's really difficult for us to move forward on any kind of unified agenda because most of the disabled women's organizations that exist are extremely local or really limited to one country. Like in Uganda, there's a Uganda Disabled Women's Organization, or in Zimbabwe, there's a Women's Project of the National Council, or in San Luis Potosi, Mexico, there's an emerging kind of volunteer group of disabled women, and in Canada there's a national disabled women's organization--DAWN--DisAbled Women's Network of Canada--but in all these cases, it's speaking to primarily physically disabled women and to people who want to get something very specific out of them--more membership-type organizations. The one in Zimbabwe's doing some leadership development as is the one in Mexico, but in general, there's not yet a network or an infrastructure for the women who are women leaders to talk to each other in an ongoing way and to work on projects together, particularly in the United States. I mean, in the U.S. it's a real hodgepodge of a couple of little itty-bitty women's projects.

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O'Toole: We're talking about the whole lack of an infrastructure for disabled women internationally, particularly for disabled women leaders to talk to each other. In the United States it's particularly abysmal. It's very difficult for disabled women to find any information about women with disabilities unless they happen to hook up with one of the few leaders. It's still very much oral, anecdotal information and networking. The mentoring is that way, too. The only real change to that has been the development of CAL-WILD which is an international disabled women's listserv that we developed in California. Suzanne Levine runs it in San Francisco, as a communication for the Beijing trip.

Jacobson: And it's spelled--

O'Toole: It's spelled cal-wild@igc.org and Suzanne is the listserv owner on that. We developed it thinking it was just going to be a California version of the Women's International Linkages on Disability, which is a nonorganization--it's a networking name. We hoped that it would be that and that we would just be the local, but nobody else ended up doing it, so CAL-WILD is now the hostess, if you will, for the world, getting information and passing information on about women with disabilities.

But that's not enough. I really wish for there to be an annual retreat for disabled women leaders in the United States, where people could come together and share resources and share information. I wish that there was an every eighteen-month or

every two-year kind of chapbook that was of position papers of what a whole group of different disabled women leaders think of a cutting edge issue that we all need to be talking about and talking to each other about. There's a lot of work that needs to be done.

Jacobson: What would that be?

O'Toole: That would be going to Barbara Waxman, Ann Finger, Cheryl Green, and Jean Lin, and all these people around the country and saying, you know, "What's happening? What are you the most worried about right now?" You know, like five years ago, the cutting edge issue for a lot of people was the whole position on the assisted suicide issue and the sort of approval that it was okay to kill disabled women or disabled girls when they hit menstruation. I mean, having people write down what they're thinking about, what's burning their brain at the moment that we should all be talking about and that we should be getting cross-educated about, that's sort of what I'm talking about--you know, Harilyn [Russo]. Just a whole bunch of people talking about, well, "What's bugging you right now? What are you worried about right now? What are you thinking about right now?" as a way to start to cross-pollinate and have a way to talk to each other. It could be literally like the equivalent of an on-line magazine, it could be a paper book; it doesn't matter what form it takes, but it's an effort that I think needs to get done.

Video Work on Current Issues

Jacobson: Is that something you're working on now?

O'Toole: Not right at the moment. Right at the moment what I'm working on is keeping the U.S. network of disabled women going. I'm going to do another conference in June the day before the Society for the Disability Studies meeting for disabled women.

I'm also working at taking the raw interview material that I have developed in the past and making it into finished training films. I've been showing--I did a rough cut on disabled women in violence which I've been showing at different conferences and gotten a lot of good feedback and I want to make the series of educational videos into a package of eight or ten topics. I have funding to finish violence and do two more topics, where footage is already shot. I want to get that done. I want to make some more stuff from what I've got.

I would like to have there be a good parenting video that's just a general short, "Look at these people, look at what they're doing," parenting video. The British folks did a nice one that discussed and analyzed the issues; I want one like the video shown at the Through the Looking Glass conference but with better footage, with better material, because that one's really hard to use and they own it. I mean, I want to make one that I can basically--that can just get around the world. And the work I do I have to do in different languages: in French, in Spanish, in English, and in sign language, so my work has to be a little bit--is a little different.

Jacobson: Where did you get that funding?

O'Toole: Well, writing foundation grants mostly.

Then the other issue that I'm really concerned about is sex education. I'm very worried at the lack of basic sexual knowledge of people in the disability community at all levels. I mean, we're a community that's at very high risk for HIV and we're a community that does almost nothing about that issue. I really want to develop some training materials that could be shown at conferences--booklets and videos that are sexually explicit that show, "Okay, this is what a female condom looks like. If you can't use your hands to put a condom on a man, or you want a female condom, this is how you can put it in. This is what you can do. This is what a condom looks like. This is what kind of protection you need for oral sex. These are behaviors that--this is what to do if urine spilled on an open cut." Just giving lots of basic information that's pretty widely available in the heterosexual community and certainly in the gay men's community and less available in the lesbian community but almost nonexistent for the disabled community.

This would be taking the Table Manners [book] off the gynecological table and putting it in a bedroom and showing people positions and different kinds of basic aspects of sex education that are around but that nobody's really talking about and using safe sex stuff for. So that's a project I want to do next. So I'm basically booked from now 'til June on existing--on either projects that I have to get done, or projects that I want to start fund raising for.

I'm also really concerned about the lack of all the recording of our history. I mean, I'm glad the oral history project's doing this stuff, but that stuff's going to be sort of locked at UC Berkeley and it's only going to involve a few people, so I'm working with Steve Dias and Pat Chadwick and their disability history.org website. And we're wanting to see

a library, and a history component, and an archive component built into something like the Ed Roberts Campus so that the community can record its own history and have access to information. And because every organization in town has done libraries and none of them are usable to the public, we'd like to try to address that issue, either as a city of Berkeley Library issue, or a UC Berkeley library issue. That's a project I really want to make sure gets happening. And raise my kid, and have a good time, get on subsidized housing, and you know, [laughs] the basics of life.

Acknowledgement of Disabled Women's Leadership

Jacobson: Corbett, is there anything you can think of that we didn't cover or any other comments you would like to make on what we covered? You have a chance when you go over the transcript, but I'm thinking of now, right off the top of your head.

O'Toole: Right. I would sort of just summarize a couple of things. One is I think that one of the things that enabled me to do what I've been able to do in my work was the early and strong presence of women's leadership, disabled women's leadership, in the disability movement. I feel like the whole thing about gender has been kind of unacknowledged, but I think that early on--having Judy [Heumann], Mary Lou [Breslin], Kitty [Cone], disabled women around--not so much Mary Lou in the pre-DREDF days, but certainly from DREDF on, and certainly Kitty in the community and Bonnie Regina--women who sort of stood up and said, "We're women, there are women's issues here, we need to be talking about women's stuff"--was very important. It was really important in terms of allowing me to develop a voice and develop a vision of disabled women's issues.

You know, some of those women were also lesbians and I think that disability history has really obscured the contributions of lesbians and the work that has been done, certainly by Kitty, certainly by Bonnie, certainly by me. There should be an acknowledgement of how much all the lesbian nondisabled women that worked at CIL in the old days contributed--all the van drivers, and all the accountants and the secretaries. There was just a sort of willingness--I mean, Joanne Loulan, who's a writer in the lesbian community talks about that, saying that lesbians are the wives for other movements, political movements, and I think it's been really true. Sue Sygall actually once said to me that she didn't like her office as much anymore because there used to be a lot more

lesbians. When there were lesbians, they were willing to work day and night for the cause because they understood the politics; and when she hired straight people, they thought it was a job--and it was just a nine-to-five job. It was an interesting perspective about people that are oppressed contributing to other people that are oppressed, even though it may not be their oppression. I think that that's really been underexplored, underdiscussed, and certainly undervalued.

In the old days, CIL used to have an awards banquet and I really wanted them to give an award to Avril Harris, you know, who's been around and been an attendant for twenty-five years. She made sure that attendant services happened and provided millions of hours of free attendant care to a lot of people and, you know, that kind of work. I mean, if she wasn't available, then Kitty wouldn't have gotten in or out of the hot tub or in and out of bed some days and couldn't have gone and done what Kitty did, so I just think that piece is pretty much underdiscussed.

It's been frustrating that the disability movement as a whole hasn't developed a gender analysis, doesn't understand that rape crisis or childcare or gynecological care are disability rights issues; they're still kind of women's issues and somebody else is taking care of them.

I think that the only community that I've been part of that's really taken on the disability issue has been the lesbian community, you know, whether it's through concerts or whether it's through political organizations, or whether it's through including access to information in different ways. That's been a pretty strong connection and I don't think that gets acknowledged hardly ever.

Yes, and I hope for better ties between communities of people that are doing the work. In my experience, things get better and are getting better all the time, it's just taking forever. [laughs] And we're all getting old and some of us are dying and you know, that part's hard. But I look at Meecha and Alva and the kids and the ones we can keep off of drugs--meaning drugs that are medically prescribed. I mean, I know a ton of kids with CP that are basically on Valium all the time. Yet there are the ones where we can keep them alive and keep their heads going and keep them in the world, they're going to be kicking our ass in a few years, going "Hey, old lady, get out of here. This is my movement and my issues and my space and I'm going to define it." [laughs]

Jacobson: Are they still putting kids with CP on Valium?

O'Toole: Oh, yes. I know a lot of children with CP--my cousin put her kid on it.

Jacobson: You're kidding!

O'Toole: No, they're using Baclofin, which is a muscle relaxant. It affects all your muscles, including your brain and your thinking processes. I have not wanted to put my daughter while she's learning to read on a drug that basically makes her space out.

Jacobson: Yes.

O'Toole: They put them on Valium and they put them on Botoxin, which is botulism; they inject botulism into their muscles. And they're still doing surgeries--

Jacobson: And why?

O'Toole: To control spasticity, to make the kid physically more malleable, looser, you know. I just interviewed a bunch of therapists because the doctors are starting to talk to me about an adductor release surgery for Meecha. The therapists, who have seen probably 100 kids, said each one of them knew one kid that actually improved from the surgery, a bunch of kids that stayed the same after they did the surgery so nothing changed, and a bunch of kids that lost function after the surgery.

So to me, the interventions that are currently available are not useful to my daughter and are not making a significant difference, and are not reflective of the way that the disabled adult community lives their lives. Disabled adults are not running around gutting on Valium because they have spasticity. So you know if it has really worked, then disabled adults would be using it. Do you know what I mean? The fact that we're giving it to kids but disabled adults are unwilling to do the same thing to themselves, like have surgeries or take Valium or shoot Botoxin into their limbs, tells me that it's not going to make enough functional difference to make it worth it for the side effects and the risks.

But yes, the CP stuff is still kind of in the dark ages, in my opinion. They're still doing cutting, which is what they did when I was a kid, and that's forty years ago. You know, basically a lot of people are just, "Cut, cut, cut," and that's the intervention of choice. No, I personally don't see anything that makes sense from a CP intervention point of view.

Jacobson: That's depressing.

O'Toole: Yes.

Jacobson: They're trying to treat it instead of making adaptations.

O'Toole: Right, and then the adaptations that CP kids need are usually physical equipment adaptations and that's the stuff where the purse strings are the tightest and under the most control. You know, like my kid needs a push chair and a power chair and a standing frame. She gets one. It's like one of those horrible menus: pick one. Unfortunately when it's your kid, and it's what she needs, that's not an acceptable answer to me.

Jacobson: Yes.

O'Toole: And you know, God forbid she needs a walker, because it's still, "Pick one." [laughs] Pick one for five years--guess what your kid's going to need for the next five years and hope that you guessed right. So I just, you know me, I pick the most expensive thing on the menu. Okay, give her a \$10,000 power chair and I'll figure out how I'm going to get the rest.

Meecha's got a wonderful physical therapist, a Japanese American woman named Esther Akiba. And so between all of us--I mean, I've actually put together--Meecha's environment is not typical of disabled kids in that her environment is much more multiracial. Her school is very multiracial and like lots of families that look like us are in her school, so that a lot of the variables that would make her life more isolating I've tried as much as possible to control for her.

Jacobson: Well, do you think we covered most of it?

O'Toole: Yes. Well, it'll help going through the transcripts because I feel like I left out details that may be relevant to particularly other people's interviews, you know, about times or places or people or whatever. Hopefully it'll stimulate me when I read through the transcript and think, "Oh, God, why didn't I tell her that, or why didn't I remember that?" particularly about the old days.

Jacobson: Okay. Thank you!

O'Toole: No sweat. Thank you.

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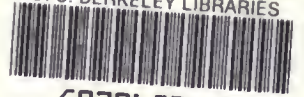
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